

96-102

**PERSONAL ASSISTANTS FOR HANDICAPPED FEDERAL
EMPLOYEES**

HEARING

BEFORE THE

SUBCOMMITTEE ON THE CIVIL SERVICE

OF THE

COMMITTEE ON

POST OFFICE AND CIVIL SERVICE

HOUSE OF REPRESENTATIVES

NINETY-SIXTH CONGRESS

SECOND SESSION

ON

H.R. 7466

A BILL TO AMEND SECTION 3102 OF TITLE 5, UNITED STATES
CODE, AND SECTION 7 OF THE FEDERAL ADVISORY COM-
MITTEE ACT TO PERMIT THE EMPLOYMENT OF PERSONAL
ASSISTANTS FOR HANDICAPPED FEDERAL EMPLOYEES BOTH
AT THEIR REGULAR DUTY STATION AND WHILE ON TRAVEL
STATUS

NEWARK PUBLIC LIBRARY

AUGUST 20, 1980

DEC 16 1980

Serial No. 96-102

U. S. GOVT. PUBS.
DEPOSITORY 376

Printed for the use of the Committee on Post Office and Civil Service



U.S. GOVERNMENT PRINTING OFFICE
WASHINGTON : 1980

67-856 0

Y 4 P 84/10:

PERSONAL ASSISTANTS FOR HANDICAPPED FEDERAL
EMPLOYEES

HEARING

SUBCOMMITTEE OF THE CIVIL SERVICE

COMMITTEE ON POST OFFICE AND CIVIL SERVICE

JAMES M. HANLEY, New York, *Chairman*

MORRIS K. UDALL, Arizona, *Vice Chairman*

CHARLES H. WILSON, California

WILLIAM D. FORD, Michigan

WILLIAM (BILL) CLAY, Missouri

PATRICIA SCHROEDER, Colorado

GLADYS NOON SPELLMAN, Maryland

HERBERT E. HARRIS II, Virginia

ROBERT GARCIA, New York

MICKEY LELAND, Texas

GERALDINE A. FERRARO, New York

DONALD JOSEPH ALBOSTA, Michigan

JOHN J. CAVANAUGH, Nebraska

GUS YATRON, Pennsylvania

MARY ROSE OAKAR, Ohio

EDWARD J. DERWINSKI, Illinois

GENE TAYLOR, Missouri

BENJAMIN A. GILMAN, New York

JIM LEACH, Iowa

TOM CORCORAN, Illinois

JAMES A. COURTER, New Jersey

CHARLES PASHAYAN, Jr., California

WILLIAM E. DANNEMEYER, California

DANIEL B. CRANE, Illinois

DAVID MINTON, *Executive Director and General Counsel*

THEODORE J. KAUF, *Minority Staff Director*

ROBERT E. LOCKHART, *Deputy General Counsel*

JAMES PIERCE MYERS, *Assistant General Counsel*

SUBCOMMITTEE ON THE CIVIL SERVICE

PATRICIA SCHROEDER, Colorado, *Chairwoman*

MORRIS K. UDALL, Arizona

HERBERT E. HARRIS II, Virginia

WILLIAM (BILL) CLAY, Missouri

GUS YATRON, Pennsylvania

JIM LEACH, Iowa

GENE TAYLOR, Missouri

CHARLES PASHAYAN, Jr., California

JAMES A. COURTER, New Jersey

ANDREW FEINSTEIN, *Subcommittee Staff Director*

CONTENTS

Statements of:	Page
Jule M. Sugarman, Deputy Director, Office of Personnel Management accompanied by Hedwig Oswald, Director, Selective Placement Pro- grams, and William R. Irvin, Assistant Director, Staffing Services.....	2
John M. Williams, director of communications, American Coalition of Citizens with Disabilities, Inc.....	16
Thomas S. Austin.....	18, 38
John Colangelo.....	28
Evan Kemp, codirector, Disability Rights Center.....	36
Leslie Milk, executive director, Mainstream.....	40
Sharon H. Wilkin, National Spinal Cord Injury Foundation.....	42
Statements and letters submitted by:	
Ray Marshall, Secretary of Labor.....	48
Kenneth Lyons, National Association of Government Employees.....	49
Frank R. DeGeorge, Paralyzed Veterans of America.....	51

(iii)

EMPLOYMENT OF PERSONAL ASSISTANTS FOR HANDICAPPED FEDERAL EMPLOYEES

WEDNESDAY, AUGUST 20, 1980

HOUSE OF REPRESENTATIVES,
SUBCOMMITTEE ON CIVIL SERVICE,
COMMITTEE ON POST OFFICE AND CIVIL SERVICE,
Washington, D.C.

The subcommittee met, pursuant to notice, at 9:40 a.m., in room 304, Cannon House Office Building, Hon. Patricia Schroeder (chairwoman of the subcommittee) presiding.

Members present: Representative Schroeder.

Also present: Shirley P. Stein, professor, Gallaudet College (interpreter for the deaf).

Mrs. SCHROEDER. I want to welcome you to today's hearings on legislation to provide needed personal assistance to disabled Federal employees. While the legislation is neither controversial nor costly, I believe that today's hearings are important. They provide an opportunity to build a legislative record affirming the policy of making whatever reasonable accommodations are necessary to employ men and women with physical disabilities.

According to data compiled by the Office of Personnel Management, some 6.74 percent of Federal workers report having some handicap. Some 50,000 of these individuals have missing extremities, orthopedic impairments, or paralysis. Yet, each of these individuals is contributing a full day's work for each full day's pay.

Each of these individuals leads an independent and satisfying life, because each earns his or her own keep. These workers, no less than other civil servants, are employed based on their skill, knowledge, and abilities. It would be grossly unfair and wasteful to the taxpayer to refuse to hire workers with disabilities because some kind of special arrangement has to be made to permit these individuals to make their full contribution to society.

The Federal Government should be the leader in employing citizens with disabilities—not only because it is morally right, not only because it will reduce governmental expenditures to support such individuals, and not only because the Government should serve as an example to the private sector of progressive employment practices.

The Federal Government should lead in this area because high quality employees with disabilities can increase the productivity and efficiency of the Federal Government. The Federal Government would be cheating itself by failing to make reasonable accommodations to employ citizens with disabilities.

I support H.R. 7466. After this hearing, I hope we can move rapidly to bring this legislation to the floor of the House.

Our first witness is Jule Sugarman, who is a good friend—the Deputy Director of the Office of Personnel Management.

Mr. Sugarman, we welcome you, and we will put your whole testimony in, and you may summarize.

STATEMENT OF JULE M. SUGARMAN, DEPUTY DIRECTOR, OFFICE OF PERSONNEL MANAGEMENT, ACCOMPANIED BY HEDWIG OSWALD, DIRECTOR, SELECTIVE PLACEMENT PROGRAMS, AND WILLIAM R. IRVIN, ASSISTANT DIRECTOR, STAFFING SERVICES

Mr. SUGARMAN. Thank you very much. I have with me this morning Mrs. Hedy Oswald, who is our specialist in the handicapped area, and Mr. Bill Irvin, from our staffing services.

Since the testimony has been inserted in the record, let me simply highlight a couple of points about it. One is that we are dealing here with a group of people who in numbers are very small. Hopefully their number will be a little larger as our program reaches out and the Federal program grows larger.

Even at the outside, I think we are talking about a small proportion of disabled workers. These are people who have demonstrated their energy, courage, and determination by performance. What we are trying to do is to provide assistance that will help them to function better. We have situations in which those employees could do a broader job or a better job if they were in a position to travel. Since that is an expensive proposition, they oftentimes cannot take a family member with them on such travel. This bill would authorize the payment of travel expenses to an assistant and would also authorize the use of an assistant in the actual employment situation.

We do not anticipate that more than 10 percent of the people involved who have these types of handicaps would actually require this assistance.

The figures which we have been able to develop as a cost estimate have a range of some \$330,000 for travel assistants' service and \$2,148,000 for assistants' service as needed on the job. Frankly, I think those estimates may be high, because these people are by and large independent in their activities and ask for help only in those situations where it is absolutely essential. Many of them function with assistance from people in the office on a volunteer basis, but there are exceptional situations where a special kind of assistance would be required.

That concludes my testimony, Madam Chairwoman. I would be glad to answer any questions, if there are any.

Mrs. SCHROEDER. I appreciate that. We will put your whole statement in the record.

Let's talk about the assistants a little bit. First, people have said what we are doing in this bill is hiring two people to do one person's job. I think we should answer that. Second, sometimes the family member is the best assistant. Does that run afoul of antinepotism laws if we were to select the family member as that assistant in the Federal Government? Third, should we have in the bill something which would waive personnel ceilings for the assistants? Will ceilings cause a problem in agencies? Will managers be afraid

to hire assistants because they might make the agency bump up against the personnel ceiling?

Mr. SUGARMAN. You have raised one good point about nepotism that I had not thought about. I guess my general reaction would be there may be some problems, but that we probably could handle it with a special regulation.

Bill, would you have any opinion on that?

Mr. IRVIN. No, not really.

Ms. OSWALD. We did waive the nepotism regulations for severely disabled students employed in summer programs, and I would assume there would be a parallel here. However, I would doubt very much that we would run into this because we really estimate that what we are authorizing here will not be some full-time positions except in rare cases. It could possibly be a family member. But I think in the main we could handle that.

Mr. SUGARMAN. Why don't I check with my general counsel and provide a statement for the record?

Mrs. SCHROEDER. That would be helpful to see whether we legally need to add anything.

Mr. SUGARMAN. On personnel ceilings, next fiscal year we will be going to a system of ceilings based on full-time equivalent employment. Since these assistants will be working very little time, I don't anticipate much of a problem. For example, if they work an hour a day, it is counted as only one-eighth of a staff-year. Any agency that is serious about it could handle the numbers involved here under existing ceilings.

Mrs. SCHROEDER. What about the charge that you will be hiring two people to do the job of one?

Mr. SUGARMAN. First of all, as we have tried to emphasize, we see this as a part-time kind of business. We don't anticipate that these individuals will be sitting there the whole day long; instead they will really be there just when those special moments of need occur.

In terms of the travel, there will be no more than two or three times a year that an individual would be engaged in travel and probably no more than 2 or 3 days at a time. We are talking about a small amount of time. It has been my experience that disabled people who have the courage and the determination to work under these conditions are extremely productive—probably more productive than the average employee.

Mrs. SCHROEDER. I think I saw in your testimony that OPM has not collected data on the hiring of interpreters for the deaf and readers for the blind; is that correct?

Mr. SUGARMAN. We do not have a collection system. That is right.

Mrs. SCHROEDER. Have you thought about collecting data in the future? If the bill passes, would you collect data on the use of personal assistants? Also, have you thought about having a pool of assistants in the Federal Government, such as interpreters for the deaf, personal assistants, and readers for the blind? Maybe a pool might be a way that you could go.

Mr. SUGARMAN. On the data collection, we are constantly torn between the desire to have data and the burden of collecting it. In this case it has been my judgment that the numbers involved will

be so small that it will not be worth imposing the administrative burden on agencies. I know it sounds like a small item, but every small item added creates additional problems for the agencies and for us to handle.

In terms of the pool, I think Hedy may want to speak to this, but we generally find there is no problem in locating people to do this kind of work.

Ms. OSWALD. The problem in establishing a pool of people is that the employees who need the services are not always in the same work area which would make this possible.

In addition to that, the need for these services is intermittent during the workday. I think there is too much of a personal nature, if you will, involved here on what kind of service is needed; for example, the wide range of ability needed from an interpreter can be all the way from a co-worker who can sign sufficiently for the everyday kinds of work, to the need for someone like our interpreter here today, who is highly skilled.

The same kind of issue applies to readers, and, of course, personal assistants' care falls into the same category.

I think that we should also keep in mind that many of the services that may be needed are performed by health units. Personal assistance care really is individualistic.

Mr. SUGARMAN. Should this bill be approved and any problems develop in identifying people, we could try other arrangements. I just don't anticipate that it will be a problem.

Mrs. SCHROEDER. One of the hard things to do in the Federal Government is to get people to change or experiment, or to try something new. This is especially true once you get outside of Washington. What incentive is there for a Federal agency to try hiring the disabled? What incentive is for them to invest in a little more equipment they might need or to hire the people who can provide these personal services? I don't see an incentive there.

Mr. SUGARMAN. I think, like a great many things with which we deal, incentive comes from awakening people's consciousness to the importance of disabled persons within our society and showing by the example of leadership from the Congress and the executive branch that their concerns need to be a matter of public concern. It would be easier to do nothing about it, but this is not the kind of society we are. I think by nature we want to face up to our problems, and want to be helpful to people who are anxious and willing to work and who simply need a little special assistance.

Hedy spends most of her time selling agencies with this concept and explaining to them that it can be done. A lot of the inaction or inertia is because people don't understand what is possible in today's world and assume there is some terrible problem when, in fact, we have many living examples of people with severe disabilities who are successfully employed.

OPM's job is to tell that story to agency headquarters and to the field staff. In general, I think the message is getting across. This bill authorizes another tool for us to help sell agencies on improving employment opportunities for severely disabled persons.

Mrs. SCHROEDER. How do the agencies receive your message?

Ms. OSWALD. With varying degrees of acceptance. I think that affirmative action requirements have been extremely helpful.

Mrs. SCHROEDER. Are there affirmative action requirements for the disabled?

Ms. OSWALD. Yes; there are. Affirmative action plans from all Federal agencies are required by the Rehabilitation Act of 1973. We used to have the compliance and oversight on this. This responsibility has moved to EEOC.

I think affirmative action requirements have been helpful, but I also think there are a lot of other things that have been very helpful. What has been going on regarding handicapped persons in areas of housing, transportation, employment in the private sector. We see a great deal on television and in other media. It is a very slow process, I must say. However, when you compare results to, say, 6 or 7 years ago, we do see improvements.

You will probably get a better feel for this from some of the other people who are here to testify today. But I do think that there are people, as Mr. Sugarman said, who are raising consciousness in the country, and I think we see it in many areas with many employers in the Federal Government. That doesn't mean our track record is all that good, but we have seen an increase in the employment of severely disabled people, and I think this is really a big step forward. Providing concrete incentives is difficult, but I don't know of any we could legislate.

Mr. SUGARMAN. As part of my duties, I sit on the Interagency Coordinating Council on the Handicapped. I have been really struck by the high level of attention this committee has brought to the issues. It is chaired by Drew Days, who is the Assistant Attorney General, and I must say it is one of the best examples of vigorous attention from the Justice Department that I have seen to program issues. They are not looking at it as lawyers but as to how we really can get this job done. The fact very high-level people are willing to spend their time on issues of this kind is a hopeful sign.

Mrs. SCHROEDER. Have you considered what hiring disabled employees might do to disability retirement?

Mr. SUGARMAN. We have had, as you know, a conflict in policies in Government, allowing people to retire on disability while at the same time urging managers to hire the disabled. We are trying to improve that situation in some of our recent efforts.

I think that the availability of this legislation would for a very small number of people be helpful in keeping them on the job. It would be another resource also to make it possible for severely disabled individuals not now in the work force to become productive employees.

Ms. OSWALD. If I might add, too, this would be of assistance for not only new hires but for people who become disabled after employment either by disease or accident. I think that the balance would be there in the sense of what you are driving at.

[The prepared statement follows:]

Statement of Julie A. Sugarman
Deputy Director
Office of Personnel Management

Before the Subcommittee on Civil Service
Of the House Post Office and Civil Service Committee
U.S. House of Representatives

August 20, 1980

ANNA CHAIRWOMAN SCHROEDER AND DISTINGUISHED MEMBERS OF THE SUBCOMMITTEE:

I appreciate the opportunity to discuss the importance that the Office of Personnel Management places upon the passage of H.R. 7466, which will authorize the employment of personal assistants for handicapped Federal employees and compensate personal assistants for Federal advisory committee members, staffs, and consultants. As you know this is a proposal initiated by the administration and introduced by the Chairwoman of this Subcommittee. The purpose of this legislation is to permit the effective utilization of the services and talents of severely handicapped employees.

This is, and is likely to remain, an extremely small proportion of the Federal work force. It is a group, however, who because of their energy, determination, and performance deserve the special considerations called for in this bill. We anticipate that agencies will use this legislation to assist individuals of demonstrated competence to function even more effectively in their jobs.

We are fully committed to assuring that the Federal personnel management system is open and free of barriers to the employment of those handicapped persons who can function at an effective level, with or without assistance. This commitment was strongly affirmed in the Civil Service Reform Act, which in part, states that all employees and applicants for employment should receive fair and equitable treatment in all aspects of personnel management without regard to handicapping condition.

In addition, the Rehabilitation Act, as amended, calls for the maximizing of employment opportunities for handicapped persons, particularly those with severe disabilities. All of the provisions and regulations which have stemmed from this Act call for employers to provide reasonable

accommodation to qualified handicapped employees. In our view, this bill does just that by providing agencies with the authority to make accommodations that are essential to certain severely disabled employees so they can perform productively on their jobs and can travel on official business.

There are several kinds of disabilities that make it difficult for handicapped persons to perform in the workplace. These are various personal services that may be needed for them to be productive. Principally, we mean assistance for persons with paralytic conditions which result in the loss of ability to move or use arms, legs, and or trunk; and, assistance for persons with missing hands or arms and one or both legs. It is important to keep in mind that not all persons with these disabilities are alike in their needs as there are vast differences among individuals. For example, certain persons with quadriplegia may need a minimum of assistance, in such activities as maneuvering in the work environment, traveling, or manipulating work materials.

Typical of the need for these services is an employee who uses a wheelchair and who requires assistance only in getting in and out of the car and being pushed to and from the worksite and the cafeteria. However, there are a few employees who may require more extensive services. These are persons who cannot independently perform their own activities of daily living and therefore, may need assistance in changing position, grooming, eating, and toileting. Some persons with missing extremities may require little help because of effective use of prostheses while others may need more extensive assistance due to an inability to use prosthetics or because such aids are not appropriate for the individual.

Precedent for establishing this authority exists in a parallel accommodation provided by the Civil Service Reform Act (CSRA) for deaf and blind persons which allows agencies to pay for the services of interpreters and readers. This legislation was intended to supplement existing authorities by providing an additional option to agencies for accommodating the needs of hearing and visually impaired employees. Enactment of H.R. 7466 would provide comparable types of support services to other disabled employees as well. In addition, the need for this new legislation arises, in part, from a decision by the Comptroller General that prohibits the expenditure

of public funds for the services of personal assistants for severely handicapped employees. Part of the decision focused on the lack of specific authorization similar to that in CSRA which provides for the employment of readers and interpreters. Without specific authorization these expenditures would also have been prohibited.

We have looked into the experiences agencies have had in providing reading and interpreting services for blind and deaf employees. Although we have not instructed agencies to collect and report data on the number of individuals hired exclusively to perform these services, we have conducted an informal survey of the 10 largest agencies to ascertain how they are meeting the needs of their deaf and blind employees.

All agencies reported that in the majority of cases these services are provided by the existing work force through a variety of ways, such as:

- assigning an employee to provide reading or interpreting services on a part-time or "as required" basis,
- providing sign language instruction at the worksite for supervisors and coworkers of deaf employees,
- obtaining reading and interpreting services provided by State vocational rehabilitation agencies, and
- purchasing special sensory devices and telecommunication equipment.

More importantly, reading or interpreting duties are being written into employee job descriptions where these special services are secondary to the principal tasks of the position. This is certainly a positive approach in that specific assignment of tasks is stated in the description as opposed to haphazardly requiring employees to perform tasks that are not clearly defined or described.

One agency reported that in addition to employing a full-time interpreter, they have established a Sensory Assistance Center which houses a number of different sensory devices including a synthetic speech output computer terminal, Kurzweil Reading Machine, and a Braille Computer Terminal for use by their blind employees. Another agency reported the purchase of five Kurzweil Reading Machines for their blind employees. All agencies reported the use of personal service contracts to purchase highly skilled

interpreting services to allow for the participation of their deaf employees in conferences and other special events.

We were able to identify only five interpreters, and five readers, one full-time and four part-time, hired under the new authority. In general, the emphasis created by these legislative provisions has been the development of a greater awareness by the agencies of the special needs of these employees.

While we have attempted to estimate costs of readers and interpreters, we have found it virtually impossible to do a cost analysis because of lack of data and the diversity of ways services are performed on the job. For example, signing and reading by coworkers no doubt provides the majority of day-to-day communications. Also, the degree of need for these services varies a great deal among occupations and grade levels.

It is anticipated that the Government-wide costs for providing personal assistant services, as called for by this proposed legislation, will be minimal. Our best annual cost estimates are \$330,000 for travel assistant services and \$2,148,000 for assistant services needed on the job. However, in practice, we believe that actual expenditures will be substantially less, principally because many of these services will be provided by the existing work force, i.e., health unit staffs and coworkers.

The tables attached to our written testimony present the assumptions and calculations which were used to derive these figures.

The travel status table reflects both a high cost estimate (\$1,231,200) and a low cost estimate (\$330,000). The high cost estimate was calculated by using the total number of severely handicapped individuals employed at GS-9 grade level and above, which is 648, plus an assistant salary of \$50.00 per day. The low cost figure was based on the number of severely handicapped persons employed in occupations that are likely to require travel, which is 200, with an assistant salary of \$25.00 per day.

We believe that annual actual costs will be less than the low estimate of \$330,000 since:

- o Most handicapped employees do not require assistant services.

- o Some employees will find other sources of assistance when traveling (i.e., friends, colleagues, relatives, and employees of hotels and transportation systems).

While we estimated the annual costs for services of personal assistants at the worksite for severely handicapped employees to be \$2,148,000, we believe the actual costs will in fact be less. As we pointed out earlier, there is a wide variance among such individuals and their needs for personal assistance. Although a few persons are likely to require full-time personal assistance, it is assumed that the majority currently function at their duty stations with either minimal or no personal support services. As with reading and interpreting services, we anticipate that the majority of services required on a day-to-day basis will be performed by other employees. In addition, modern technology has produced equipment that increases the independence of severely disabled people, i.e., electric wheelchairs, adapted telephones and dictating machines, and aids for turning pages.

In conclusion, I wish to emphasize again the importance we place upon the passage of H.R. 7466. In our view, the services that would be authorized are essential and will contribute to the productivity and work effectiveness of many talented, although disabled, members of the Federal work force, and those handicapped individuals who serve on advisory committees. It is a matter of equity that we begin to provide services to physically handicapped employees in the same way as we now provide services for blind and deaf persons. This legislation would end a system of treating the needs of handicapped employees differently depending on the nature of the handicap.

Thank you for the opportunity to appear here today. I will be happy to answer any questions you might have.

Attachments

TABLE I

Potential Cost of Providing Personal Assistant Services for Severely
Handicapped Federal Employees on Travel Status

Assumptions

1. A handicapped employee who requires assistant services when traveling is likely to be employed in a profession that requires minimal travel.
2. Employees in professional positions will travel on the average of three times per year.*
3. The average time in travel status is 10 days per year.
4. The cost of assistant care varies from \$25.00 - \$50.00 per day.

Cost Variables

- | | |
|------------------------------------|-----------------------|
| 1. Number of days on travel status | = 10 days |
| 2. Assistant salary | = \$25 - \$50 per day |
| 3. Assistant per diem | = \$50.00 |
| 4. Assistant travel cost | = \$300.00 |
| 5. Number of trips | = 3 trips |

Cost Determination Formula

Cost per handicapped employee is determined by the number of days on travel status multiplied by the sum of assistant salary and per diem plus the assistant travel cost multiplied by the number of trips, or algebraically:
 $(1) \times [(2) + (3)] + [(4) \times (5)]$.

Actual Annual Cost per Employee for Assistant Services

Cost = $10 \times (\text{Salary} + \$50.00) + (\$300.00 \times 3) = \$1,900 @ \$50.00 \text{ per day assistant salary or } \$1,650 @ \$25.00 \text{ per day.}$

Number of Severely Handicapped Employees

Estimate 1 - 648 (Number of severely handicapped employees at GS-9 and above)

Estimate 2 - 200 (Number of severely handicapped employees in selected occupations)

*Best available data based on a draft General Accounting Office report, titled, Increased-Productivity in Processing Travel Claims and Cut Administrative Costs in Half.

Total Annual Cost

Total annual Government-wide cost equals the cost per employee multiplied by the number of employees.

<u>Cost</u>	<u>Salary Rate</u>	<u>Annual Assistant Salary</u>	<u>Number of Severely Handicapped Employees</u>
\$ 380,000	\$50/day	\$1,300	200
\$1,231,200	\$50/day	\$1,300	648
\$ 330,000	\$25/day	\$1,050	200
\$1,069,200	\$25/day	\$1,050	648

Low cost estimate: \$330,000

High cost estimate: \$1,231,200

Comments

In practice, we believe that the actual annual cost will be less than the low estimate (\$330,000) for the following reasons:

1. Most handicapped employees do not require assistant services.
2. Some employees will find other sources of assistance when traveling (i.e., friends, colleagues, and employees of hotels and transportation systems).

TABLE II

Estimated Cost of Personal Assistants
for Severely Physically Handicapped
Employees at Duty Station

Initial Cost Assumptions

1. The following groups of employees are the most likely to require personal assistants:
 - Employees with partial or complete paralysis affecting major parts of the body.
 - Employees missing extremities.
2. It is estimated that no more than 10 percent of such employees will require an assistant.
3. The average annual salary for assistants will be approximately \$10,000 (GS-4, Step 1) or \$12,000 including benefits (at 20 percent).

Cost Estimates

<u>Handicap</u>	<u>Number of Employees Governmentwide</u>	<u>10 Percent of Employees</u>	<u>Salary and Cost per Assistant</u>	<u>= Total Cost</u>
Partial or complete paralysis of major parts of the body	1470	147	\$12,000	\$1,764,000
Specified missing extremities	318	32	\$12,000	\$384,000
Total	1788	179		\$2,148,000

Cost Estimate Reduction Issues

1. It is estimated that 90 percent of all persons employed to perform personal assistance tasks will perform other duties, primarily clerical.
2. As with reading and interpreting services, we anticipate that in the majority of the cases requiring day-to-day assistant services at the worksite that these duties will be included in other job descriptions and performed by existing employees.
3. Another existing resource to provide assistant service of a more personal nature at the worksite is the health unit. Agencies are required to provide medical care for 300 or more Federal employees located in a common area. The majority of agencies have health units located at the place of employment.
4. The Bill does not contain an appropriation. Implementation will be from existing agency funds.
5. Personnel ceilings will not change as a result of this Bill. To the extent that ceilings do change this will be a result of an administrative decision by the Office of Management and Budget that ceiling relief is

warranted for effective implementation of this Bill. To date we know of no relief granted to implement the hiring of readers and interpreters for blind and deaf persons.

Source: Statistical Profile of Handicapped Federal Civilian Employees, United States Office of Personnel Management, February 1980, Appendix B.

TABLE III

Severely Physically Handicapped Federal Employees Who Might Benefit from Assistant Services by Reported Disability and by GS Grade Level.

Reported Disability	GS-Grade Level Grouping				Total GS-9 and Above	Total Number of Employees Governmentwide
	9-11	12-13	14-15	16-18		
Missing both hands or arms	9	1	1	-	11	37
Missing both feet or legs	41	30	4	1	76	181
Missing one hand or arm and both feet or legs	3	1	-	-	4	38
Missing both hands or arms and one foot or leg	1	-	1	-	2	21
Missing both hands or arms and both feet or legs	2	2	-	-	4	41
Partial paralysis of three or more parts of the body	123	109	33	3	268	657
Complete paralysis of both legs	47	32	7	-	86	258
Complete paralysis of lower half of the body including legs	76	45	17	1	139	415
Complete paralysis of three or more major parts of the body	27	23	8	-	58	140
Total	329	243	71	5	648	1,788

Source: Data obtained from the Central Personnel Data File used in preparation of, Statistical Profile of Handicapped Federal Civilian Employees, United States Office of Personnel Management, February 1980, Appendix B.

LL IV

Severely Handicapped Employees in
Selected Occupations

OCCUPATIONS	MISSING BOTH HANDS OR ARMS	MISSING BOTH FEET OR LEGS	MISSING ONE HAND OR ARM AND BOTH FEET OR LEGS, OR BOTH HANDS AND ONE FOOT OR LEG, OR BOTH HANDS OR ARMS AND BOTH FEET AND LEGS	PARTIAL PARALYSIS OF THREE OR MORE PARTS OF THE BODY	COMPLETE PARALYSIS OF LOWER HALF OF THE BODY OR PARALYSIS OF LEGS	COMPLETE PARALYSIS OF THREE OR MORE MAJOR PARTS OF THE BODY	TOTAL
Computer Specialist	0	3	2	17	9	6	37
Contract Procurement Medical Officer	0	4	0	4	9	0	17
Quality Assurance	0	2	1	3	6	4	16
General Engineering	0	1	1	4	1	0	7
Electronics Engineer	0	1	0	3	5	1	10
Internal Revenue Agent	0	2	0	0	3	2	7
Training Instructor	0	2	1	1	14	0	18
Management Analysis	0	0	0	5	1	1	7
Program Analysis	0	0	0	8	1	1	10
Personnel Management	0	0	1	3	2	2	8
Budget Administrator	0	0	0	3	0	0	3
Administrative Officer	0	0	0	3	4	1	8
Aerospace Engineer	0	1	0	2	5	0	8
Mechanical Engineer	0	1	1	2	3	0	5
Chemistry	0	3	0	3	3	1	11
Gen. Attorney	0	1	0	4	5	1	12
	1	22	8	67	77	25	200
Total							

Source: Statistical Profile of Handicapped Federal Civilian Employees, United States Office of Personnel Management,
February 1980, Appendix C.

United States of America
**Office of
 Personnel Management**

Washington, D.C. 20415

AUG 27 1980

Honorable Pat Schroeder
 House of Representatives
 Washington, D.C. 20515

Dear Ms. Schroeder:

This responds to your inquiry concerning H.R. 7466 which would authorize the Federal government to pay for the services of a relative to attend a handicapped employee while on travel for the government. Specifically, you wish to know whether such an arrangement would violate the nepotism statute, 5 U.S.C. §3110, or Office of Personnel Management (OPM) regulations. 5 C.F.R. Part 310. OPM has determined that the proposed language would not violate the nepotism statute or our regulations.

H.R. 7466 provides that heads of agencies may employ or assign personal assistants to handicapped employees traveling in order to perform a government function. The heads of agencies would be authorized either to pay the travel expenses and per diem to other Federal employees, who accompany a handicapped employee, or to issue a travel order to the handicapped employee. The travel order would provide for direct payment or reimbursement for the personal services of an individual to accompany the handicapped employee during the authorized travel period. In the latter case, the personal assistant would not be considered a Federal employee, except purposes of 5 U.S.C. Chapter 81 (relating to compensation for injury) and 28 U.S.C. §§2671-2680 (relating to tort claims).

Both section 3110 of title 5, United States Code, and 5 C.F.R. Part 310 provide that a "public official," as defined in the section, may not appoint, employ, promote, advance, or advocate for appointment, employment, promotion, or advancement, in or to a civilian position in the agency in which he or she is serving or over which he or she exercises jurisdiction or control, any individual who is a relative of the "public official." Other sections proscribe such appointments and prohibit the payment of compensation to individuals so appointed.

In the situation addressed in H.R. 7466, the personal assistant would not be a Federal employee, except for specific and very limited purposes. Thus, because the personal assistant is not appointed to a position in the Federal government, no nepotism problem would arise. Moreover, even if the nepotism statute is applicable, in the vast majority of cases no violation of the statute would occur because the handicapped employee would not be a "public official" as that term is defined in 5 U.S.C. §3110.

I would also like to point out that the appointment, employment, promotion, or advancement of a relative is also a prohibited personnel practice under 5 U.S.C. §2302(b)(7). However, as you know, the interpretation and investigation of prohibited personnel practices lies within the jurisdiction of the Special Counsel, of the Merit Systems Protection Board, so I am unable to comment upon this aspect of your question.

I trust the foregoing will be of assistance to you.

Sincerely yours,

Jule Sugarman
 Jule Sugarman
 Deputy Director

Mrs. SCHROEDER. Let me thank all of you for being here this morning. We appreciate your testimony, and we will look forward to your further statement about the nepotism issue. Also, we would appreciate any suggestions you might have that would make the legislation better before we send it out.

The next witness is John M. Williams, who is the director of communications of the American Coalition of Citizens With Disabilities.

STATEMENT OF JOHN M. WILLIAMS, DIRECTOR OF COMMUNICATIONS, AMERICAN COALITION OF CITIZENS WITH DISABILITIES, INC.

Mr. WILLIAMS. Chairwoman Schroeder, members of this distinguished subcommittee, good morning. I want to thank you for allowing me this opportunity to submit testimony on H.R. 7466, a bill that will allow the employment of personal care assistants for handicapped Federal employees both at their regular duty station and while on travel status.

I am John Williams, director of communications for the American Coalition of Citizens With Disabilities. The coalition is a national umbrella association of 85 National, State, and local organizations representing approximately 7.5 million disabled people of various disabilities. The coalition strives to enhance the human and civil rights of disabled people through promotion of consumer and professional involvement in decisionmaking on National, State, and local levels.

The coalition lauds H.R. 7466 and wholeheartedly endorses its passage.

H.R. 7466 shows a renewed commitment on the part of this subcommittee and Congress to allow disabled people employed by the Federal Government to become full participants in the Federal process. It is a reaffirmation of section 504 of the 1973 Rehabilitation Act, a law regarded by millions of disabled people as their civil rights legislation.

According to a 1976 survey of income and education conducted by the Bureau of the Census, several million people with severe disabilities who are educated, highly motivated, and qualified for Government employment are currently prohibited from working due to the unavailability of personal assistants to attend to their needs while on the job or on travel. This is a devastating waste of human resources. These persons, who desire to work and are highly qualified to do so, are instead consistently denied jobs. Rather than working and paying taxes, they are forced to sit home and collect Government compensation.

In addition, the 1976 survey indicated that after the onset of a disability, 11 percent of the workers were forced to switch to less prestigious jobs. Of the various categories of workers, which included professional and managerial, clerical and sales, craftsman and operatives, farmers and farm laborers and service workers and laborers, the professional and managerial personnel were most likely to shift to less prestigious occupational categories. In addition to these workers, thousands more workers who became disabled on their jobs were forced into an early retirement.

The passage of H.R. 7466 will be a giant step toward alleviating these travesties. It will have the following consequences:

It will increase the performance capabilities of disabled persons, therefore allowing them greater latitude in performing their duties.

It will provide disabled people with the opportunity to achieve higher levels of responsibility and management positions within the Federal Government.

It will expose larger numbers of people throughout the country to the abilities of disabled people as a result of increased employment and increased travel opportunities for disabled employees.

It will relieve the economic burden from disabled people who traditionally have had to pay for personal care attendants, at a cost so prohibitive that it took, and continues to take, too many of them out of the work force.

It will allow for job opportunities in the Federal Government for handicapped people requiring personal care attendants.

It will set a precedent for State and local governments to follow, and give an impetus for business and labor to do the same.

It will reduce the number of unemployed disabled people living on Federal assistance programs, thus enabling them to become taxpayers.

It will increase employment opportunities for personal care attendants, thus reducing the unemployment roles.

It will allow persons who become disabled on the job to continue working in their field of expertise, rather than being forced to find a new job or retire on disability status. This opportunity will benefit not only the disabled worker, but the employer as well, who is spared the time-consuming task of recruiting and training a new employee.

Lastly, as stated earlier, it reaffirms the Federal Government's commitment to stand behind section 504 of the Rehabilitation Act of 1973—the civil rights law for every disabled person in the country.

For all of these reasons, Chairwoman Schroeder and distinguished members of this subcommittee, I urge, on behalf of the millions of severely disabled Americans who will benefit from this valuable legislation, your support for H.R. 7466. I thank you for your commitment to encourage and stimulate job opportunities for American citizens and for the opportunity to speak to you this morning in support of H.R. 7466.

Mrs. SCHROEDER. Thank you very much, Mr. Williams. Since we are on the same side, both pushing for H.R. 7466, it is hard to think of any questions.

I think the main thing your group could help us to do is to make everyone aware the legislation is here and try to help us get some votes. I suppose if you can think of other things the Government could do to help bring more disabled people into the work force, we would really appreciate it. What incentives can there be to make managers more sensitive? If you know of anything, we would be happy to have you tell us. If you see things that we could do to help even more than this bill, we would surely like to know.

Mr. WILLIAMS. I think the Government should really begin to look into its hiring practices regarding people who are handi-

capped. I think it needs to be more sensitive to the special needs of handicapped people, and it needs to really cut out a lot of the red-tape, a lot of the bureaucracy.

If the Government wanted to, it could use within its own offices its own people to train them to become interpreters, to have secretaries be the readers, to actually train Federal employees to become personal care attendants.

I think the Government says one thing and basically practices another. It will use a lot of excuses not to fulfill its obligations, and I think we need to find out why.

We need also to educate people within Government and to do more sensitizing.

Mrs. SCHROEDER. I appreciate that. You can keep educating us. We will work very hard to get this passed, and we appreciate your group educating and sensitizing us so we can make it a better workplace.

Thank you very much for appearing this morning, Mr. Williams.

The next witness we have this morning is Dr. Thomas S. Austin. Dr. Austin, we are very happy to have you here.

STATEMENT OF DR. THOMAS S. AUSTIN

Dr. AUSTIN. Madam Chairperson and members of the committee, I appreciate this opportunity to briefly comment on H.R. 7466, a bill to permit Federal agencies to hire personal assistants for handicapped Federal employees.

Throughout my prepared statement you will note the words "Madam Chairperson." This is the first time I have appeared before Congress since I retired. I called three agencies to find out the correct way to address you. I was informed that Madam Chairperson was correct. I wish I had followed your counsel's suggestion that I use, "Chairwoman." So throughout my testimony, please correct as appropriate.

Mrs. SCHROEDER. Don't worry about that.

Dr. AUSTIN. There are two words that I will use, and other people have used; they are, assistance, a-n-c-e [spelling] and assistants, a-n-t-s [spelling]. I think we should be careful because assistants means bodies and assistance means the activities. I hope you will see there is a bit of difference, and that it will have some significance.

A brief note of background. You will note from my curriculum vitae that when I had polio in 1951, I had completed my formal education, and my training as an oceanographer, 5 years of which were with the Government. In 1952, immediately after polio, I joined the Bureau of Commercial Fisheries, Department of Interior, in Honolulu, and remained with the Federal Government until my retirement in 1979.

For 27 years, I worked from the wheelchair. I mention this only to indicate that in my particular case—I am here speaking as an individual, not as a representative of any particular group of people—that I had the advantage in that my education and my experience as an oceanographer were behind me. We have to think also of those who are entering employment who have not had the full advantage of both formal education and experience and a mixture of the two.

I must say that during the period in the wheelchair with the Government I had no major problems primarily because of enlightened management which I hasten to admit is not the norm. There are problems with individuals in middle and upper management levels in the manner in which they encourage, or discourage, disabled people to seek employment with the Government or, once employed, to support them.

Until recently there had been no reliable statistics concerning the number of disabled Federal employees. My personal observations during the 27 years suggests there were very few disabled people, particularly among scientists and support technicians, the group with whom I have had the most experience.

I did not know, for most of that period, of a single oceanographer, which was my chosen profession, who was disabled, this fact due to the attitude if an oceanographer can't go to sea, he can't be employed as an oceanographer. Of course, that is not true, because there are numbers of projects that disabled people trained in oceanography can handle.

The first reliable statistics were prepared by Ms. Oswald, who spoke to you earlier this morning. She suggests that there are 134,026, which is a rare statistic. I will always wonder how she arrived at that 26, but I have learned over the years not to argue with Hedy.

A very small percentage of this number needs assistance or assistants. Her estimate this morning was 648 GS-9 and above from which a total of 200 would need help during travel.

I am sure that the number of handicapped, employees in the Federal Government has and will continue to increase as a result of Public Law 95-112 and sections 501 through 504. Certainly with the passage of your bill, it will receive even more emphasis.

One very heartening sign is the changes with respect to barrier-free environment. Employees in wheelchairs, those who are orthopedically handicapped are beginning to move around Government buildings more freely. This morning, in coming here, the guards were very gracious. We went to a ramp; we had no problems whatsoever. I can remember not too long ago that was not the case.

Motivation and resources certainly will assist in reducing the physical-type barriers. But of more concern to me and most handicapped individuals, disabled individuals, are the attitudinal barriers. These are barriers in people's minds. These are far more difficult to overcome.

In working with disabled children who are interested in becoming scientists there is constantly the belief that you cannot turn a disabled individual or deaf or blind person loose in a laboratory.

Mrs. SCHROEDER. I am going to have to interrupt you. That, unfortunately, is a second bell which means I have to run over there to vote. We will have a 10-minute recess.

[Brief recess.]

Mrs. SCHROEDER. Again I apologize for the interruption. We appreciate what you are saying. Dr. Austin, would you like to continue?

Dr. AUSTIN. Thank you, Madam Chairman.

I think when rollcall came I was just discussing problems of both the physical and attitudinal barriers and I mentioned, at least in

my judgment, the attitudinal barriers toward the sciences are far more difficult to lower than the physical because of the attitude that young people who are blind or deaf cannot function in laboratory environments. Such is not the case.

Enactment of 7466 will certainly provide for a means whereby handicapped civilian employees may more effectively utilize their education, training and expertise. Provisions of the bill will also enhance opportunities to further people's education and on-the-job training and thus insure, in many cases, opportunities for both career development and promotion.

Were statistics compiled concerning promotional records of disabled people in the Federal Government, I think we might be a little distressed. I don't have such statistics. Personal observations suggest that promotional opportunities are far less for those in the Federal Government than for their able-bodied counterparts. I think your bill will certainly help this.

There will be more opportunities for qualified—and in my notes I have underlined the word because I stress it—handicapped persons to enter the civilian Federal Service. Assistants as may be required would be authorized.

Many college graduates, with various types and degrees of disabilities who are entering the job market in ever-increasing numbers as a result of implementation of title 5, Public Law 93-112, as amended, of the activities of the AAS Office of Opportunities in Science and the Foundation for Science and the Handicapped, Inc.—would be hired as scientists and technicians by the Federal Government.

There are several reports available. One comes to mind from the American Association for Advancement of Science, Office of Opportunities. They have a directory of disabled scientists throughout the United States. The directory includes over 500 professional scientists who are disabled in some way. They have another 600 on file for update.

The Foundation for Science of the Handicapped, with whom I am involved, also represents about 500 disabled professional scientists.

Each of these individuals really is a role model. When people ask, how can you be sure that a disabled individual at what would be a reasonably high GS grade level can function effectively, role models are available throughout our Nation in all the sciences.

Job descriptions of present employees, it seems to me, could be amended to reflect the nature of the assistance which could be provided to those already on board or those to be hired after enactment of 7446. Of particular significance will be technicians to assist professional scientists in the laboratory environment in many cases mandatory, if these disabled professional scientists are to be able to use their expertise in behalf of our Nation.

Many handicapped scientists among my acquaintances have unique talents and qualifications. Were they employed by the Federal Government, it would be in our Nation's best interests for them to travel—throughout the 50 States and to other nations.

Assistants may be required for them to function more effectively. Such assistance may be provided by a person already employed. If the person is not on board the enactment of the law would provide

for individuals to accompany, if it is in the best interest of the Government, the handicapped person in travel status.

I would emphasize in closing, Madam Chairwoman, that training for the managers involved with handicapped individuals is a must. Very often it is difficult for a manager, particularly middle level management, to accept the handicapped individual on their staffs.

Federal managers, personnel officers, those responsible for interviewing the prospective candidates, all should be trained in this particular type of awareness.

It is very difficult at times for an individual when interviewing a prospective applicant who is blind or deaf or has cerebral palsy who may be a very competent scientist or prospective employee to understand that these people can function with but a modest amount of assistance. Maybe it is just as simple as helping the person out of and into the car.

I think that type of training in awareness must be provided along with other provisions in the bill.

I certainly appreciate this opportunity to discuss my thoughts with you—they are my thoughts. They do not necessarily represent the foundation or any group. I would be more than pleased to answer any questions if at all possible.

Mrs. SCHROEDER. Thank you, Dr. Austin, for being here. We really appreciate it. I think one of the most important things you have pointed to is with barrier-free architecture more and more disabled people are able to function. A lot of those old stereotypes will break down, and managers will not be so paralyzed by the stereotyped thinking.

You mentioned the difference between assistance and assistants. How highly trained do assistants have to be? Are we talking about people who are nurses? How do we train them? Can anyone do it?

Dr. AUSTIN. It is difficult to generalize but we may use examples. I had help frequently in and out of the car in the morning and evening. That was done by people with whom I worked. It is not difficult for two people on the way to their cars to help me into my car. My wife would very often do the driving. That took 15 minutes training but it enabled me to get into the building to my desk and enabled me to get out of the building into my car.

The NOAA laboratory in Boulder provided sign language training on a volunteer basis during lunch periods. Several of the people in the laboratory took advantage of this. Of course, they were not as skilled as the young lady here on my left but they were able to converse with the deaf employees and they became more adept as they practiced. It didn't take much effort.

I think assistance can be provided in that matter and as to assistants, it seems to me in most cases position descriptions of presently employed individuals could be changed.

A good example, if I may with my personal experience, one of the conference rooms I frequently had to go to had steps. To help me up those steps meant they picked up me and the wheelchair and carried me. For a variety of reasons—I think I added a few pounds in the last few years—it became increasingly difficult. Position descriptions were changed in order to protect these individuals if they were injured in any way in helping me in this manner. It was a very simple thing to do.

From that time on there was absolutely no problem while I was with that particular group of people.

With assistance I would primarily have travel status with an individual who would go along with a disabled employee whose travel was in the best interests of the Government. Certainly it is not in the best interests of the Government for all disabled people to travel but there are some who have an expertise that is needed internationally for whatever the purpose may be. That is where the assistants may come in.

As to hiring an individual full time to support a disabled person on the staff of a Federal organization, that, in my thinking, would be rather unique.

Mrs. SCHROEDER. That may be the old stereotype.

Dr. AUSTIN. It might well be. I was with the public nurse when needed in our building. She was fabulous.

Mrs. SCHROEDER. But she was there before you came and was there for everyone.

Dr. AUSTIN. Oh, yes, and is still there. The point is she knew me, knew such problems as I potentially could have being in a wheelchair so when anything happened she was always upstairs in moments. Nothing ever happened.

Mrs. SCHROEDER. That is true of every employee here to some extent.

Dr. AUSTIN. Surely.

Mrs. SCHROEDER. Thank you again so much. We really appreciate it.

[The prepared statement follows:]

STATEMENT

OF

DR. THOMAS S. AUSTIN

CONCERNING

FEDERAL AGENCIES HIRING PERSONAL ASSISTANTS
FOR HANDICAPPED EMPLOYEES

BEFORE THE

COMMITTEE ON POST OFFICE AND CIVIL SERVICE
SUBCOMMITTEE ON CIVIL SERVICE

UNITED STATES HOUSE OF REPRESENTATIVES

AUGUST 20, 1980

Madame Chairperson and Members of the Committee:

I appreciate this opportunity to briefly comment on H.R. 7466, a Bill to permit Federal agencies to hire personal assistants for handicapped Federal employees.

I have prepared and submitted to the Committee a transcript of my remarks. With your approval, Madame Chairperson, I propose that my prepared remarks be entered into the record and that I present only the highlights here today.

May I refer to the curriculum vitae. You will note that I had polio in 1951. At that time, I had completed my formal education and had been employed as an Oceanographer since 1944, including five years with the Department of the Navy. In 1952, I joined the Bureau of Commercial Fisheries, Department of Interior (now National Marine Fisheries Service, Department of Commerce) Laboratory in Honolulu, Hawaii. I remained in the Federal Service until my retirement in July of 1979. Thus, for a period of twenty-seven years, I worked from the wheelchair. At no time during these twenty-seven years was I unable to carry out my duties as a result of inadequate assistance, whether these duties involved work in the office, a variety of conferences and meetings, or travel throughout the United States and abroad. I would hasten to mention, Madame Chairperson, that this situation resulted from enlightened and understanding managers. I regret that I am unable to state that this was the norm. The legislation which you have proposed will authorize and facilitate assistance as may be needed to the handicapped Federal civilian employees.

Until recently, there have been no reliable statistics concerning the number of disabled Federal employees. My personal observations suggest that, at least during most of the twenty-seven years, there were very few such employees, particularly among scientists and support technicians. To narrow the field a bit more, I did not know of a single Oceanographer in the Federal Service who was handicapped. The first reliable data were compiled by Ms. Hedwig Oswald of the United States Office of Personnel Management. Her most recent estimates (in "A Statistical Profile of Handicapped Federal Civilian Employees, 1979") was that there were 134,026 handicapped Federal civilian employees, 6.4% of the work force.

I am sure it is safe to assume, Madame Chairperson, that the number of handicapped civilian employees in the Federal Service has, on the average, increased due to the implementation of Public Law 95-112, as amended, The Rehabilitation Act of 1973 (Title 5, Sections 501-504, particularly 501).

Changes in order to achieve barrier-free environments (Title 5, Section 504) and program access, plus those to alleviate attitudinal barriers, individually and collectively, have paved the way to the employment of greater numbers of handicapped persons. Motivation and resources will assist in removing physical barriers. Resources, understanding and appreciation of the fact that handicapped persons can work along side of, and on par with, their non-handicapped co-workers will further the lowering of attitudinal barriers.

Enactment of H.R. 7466 will provide for means whereby handicapped civilian employees may more effectively utilize their education, training and expertise. Provisions of the Bill will enhance opportunities to further their education and on-the-job training, thus ensuring, in many cases, opportunities for both career development and promotion. Of equal and possibly greater significance, Madame Chairperson, there undoubtedly will be more opportunities for the qualified handicapped person to enter the civilian Federal Service. Assistants as may be required would be authorized. Many college graduates, with various types and degrees of disabilities who are entering the job market in ever-increasing numbers as a result of implementation of Title 5, Public Law 93.112, as amended, of the activities of the AAAS Office of Opportunities in Science and the Foundation for Science and the Handicapped, Inc., would be hired as

scientists and technicians by the Federal Government. As applicable, job descriptions of present employees would be amended to reflect the nature of the assistants and assistance to be provided to those already on board or to those hired after enactment of H.R. 7466. Of particular significance will be technicians to assist professional scientists in the laboratory environment(s).

Many handicapped scientists among my acquaintances have unique talents and qualifications. Were they employed by the Federal Government, it would be in our nation's best interests for them to travel--throughout the fifty States and to other nations. Assistants may be required for them to function more effectively. Such assistance may be provided by a person already employed. Their job description should be appropriately modified. If the person in question were not employed by the Federal Civilian Service, resources would be provided to cover the cost of their travel expenses. H.R. 7466 addresses both situations.

Following enactment of the legislation, training for managers must be provided. The assistance to be authorized will not be effectively administered unless Federal managers have an awareness that hiring qualified handicapped persons and providing them with assistance as may be required is definitely in the best interests of the Federal Government of our nation.

My thanks to you, Madame Chairperson, and to the members of the Committee, for your interest and patience. H.R. 7466 is another piece of important legislation that will provide for equal employment rights for handicapped persons in the Federal Civilian Service.

SELECTED SPECIAL ASSIGNMENTS

Member, U.S. Delegation, Organizational Meeting of the Intergovernmental Oceanographic Commission, Copenhagen, 1960.

Member, U.S. Civil Service Commission Board of Examiners for Fishery Biologists, 1962-1965.

International Coordinator, Intergovernmental Oceanographic Commission, International Cooperative Investigations of the Tropical Atlantic, 1962-64.

Member, National Academy of Sciences, National Research Council, Division of Earth Sciences, 1963-1965.

Chairman, U.S. Delegation, Intergovernmental Oceanographic Commission, International Coordination Group Meeting for International Cooperative Investigations of the Tropical Atlantic, Paris, June 1963 and June 1967.

Chairman, Intergovernmental Oceanographic Commission, Working Group on International Oceanographic Data Exchange, June 1968-1976.

Member, Editorial Board, OCEANIC INDEX and OCEANIC CITATION JOURNAL, 1969-1973.

Member, Intergovernmental Oceanographic Commission/World Meteorological Organization Joint Panel of Experts, Coordination of Requirements, Integrated Global Ocean Station System, Geneva, 1969, and Paris, 1970.

Chairman, Advisory Committee, Environmental Sciences, Washington Technical Institute, 1972-1975.

Rapporteur, Intergovernmental Oceanographic Commission/Food and Agricultural Organization of the United Nations Program, Ocean Sciences as Related to Fishery Sciences, Paris, 1980.

President, Foundation for Science and the Handicapped, Inc., 1980.

Member, Governor's Committee for Employment of the Handicapped, 1980.

Member, Advisory Board, AAAS, Project on the Handicapped in Science, Office of Opportunities in Science, 1979-present.

Member, President's Committee for Employment of the Handicapped, 1966-present.

Member, Advisory Board, Johns Hopkins University, Use of Personal Computers to Aid the Handicapped, 1979-1980.

CURRICULUM VITAE

<u>Name</u>	Dr. Thomas S. Austin
<u>Date and Place of Birth</u>	October, 10, 1915 Olean, New York
<u>Wife</u>	Gretta Jane (Martin) Austin
<u>Education</u>	BA Biology 1938 Grove City College MA Zoology 1940 University of Buffalo MS Limnology 1942 Yale University DSc (Hon.) 1963 Grove City College
<u>Employment</u>	Oceanographer, Woods Hole Oceanographic Institution Oceanographer, Naval Hydrographic Office Oceanographer, Bureau of Commercial Fisheries Biological Laboratory, Honolulu Assistant Director, Bureau of Commercial Fisheries Biological Laboratory, Honolulu Assistant Director, Bureau of Commercial Fisheries Biological Laboratory, Washington, D.C. Director, Bureau of Commercial Fisheries Biological Laboratory, Washington, D.C.

Director, Bureau of Commercial Fisheries
Tropical Atlantic Biological Laboratory,
Miami

Director, National Oceanographic Data
Center and World Data Center A for
Oceanography

Director, Environmental Data and Infor-
mation Service

Awards

Citation from Honolulu Federal Business
Association as Federal Employee of
the Year - 1960

U.S. Navy's Outstanding Federal Handi-
capped Employee - 1969

Finalist, Federal Outstanding Handicapped
Employee - 1969

Outstanding Alumni Achievement Award,
Grove City College - 1972

Department of Commerce Gold Medal -
1975

President's Award for Distinguished
Federal Civilian Service - 1980

The Society of the Sigma Xi

American Meteorological Society

New York Academy of Sciences

Marine Technology Society

American Society of Limnology and
Oceanography

American Society for Oceanography

Gulf and Caribbean Fisheries Institute

American Geophysical Union

Membership in Scientific Organizations

No. of Publications Authored or Co-authored

53

Mrs. SCHROEDER. The next witness that we have this morning is John Colangelo. John, we are very happy to have you this morning and are anxious to hear what you have to say.

STATEMENT OF JOHN COLANGELO

Mr. COLANGELO. Madam Chairperson, I appreciate you and the rest of the subcommittee giving me the opportunity to speak here today in support of H.R. 7466, the bill which will permit the employment of personal assistants for handicapped Federal employees.

For the past 6 years, my family and I have been exposed to the field of rehabilitative medicine, due to a tragic and senseless gun shooting of one of my brothers, an innocent bystander, which has since left him a quadriplegic and paralyzed from the neck down. For the last 4 years, I have been a medical and personal assistant, working on a one-to-one basis with severely physically disabled people.

My expertise centers around high spinal cord injured, quadriplegics, who have very limited or no functional use of both upper and lower limbs.

At present, I am also writing a training manual for attendants wishing to work with high spinal cord injured individuals. For these disabled people, daily personal care cannot exist without the aid of trained, professional assistants.

Similarly without the help of a trained assistant, severely physically handicapped individuals would find it most difficult, if not impossible, to seek gainful employment and try to lead productive and rewarding lives.

H.R. 7466 is, in my opinion, the answer to one of the leading problems of severely physically disabled people seeking employment. By permitting trained and qualified personal assistants to be hired, the incentive and means for severely physically disabled individuals to work will exist, thus drawing a number of welfare-dependent people into the job market.

These severely physically handicapped people do not seek nor demand jobs because of their disability. They are people who will have the skills and mental capacities for a given job; what they lack is simply the physical means to permit them to work. What severely physically handicapped people are saying is: help us with our physical necessities and we will help you with our mental and occupational abilities.

Without any question, for some severely physically handicapped people a full-time personal and medical assistant is necessary to ensure their survival, be it at home or on the job.

At present, except for readers for the blind and interpreters for the deaf, there is no legislation in the Federal civil system which permits the employment of personal assistants to assume that an individual with little or no physical movement from the neck down would need much more constant care than a blind or deaf individual.

It is my feeling that without a personal assistant, a severely physically disabled person has three choices in choosing their occupational lifestyle: They can seek employment with the help of a constant stream of volunteers around the office taking care of

personal, medical and professional needs; they can seek employment and hire an assistant to help them, paying the assistant from their own funds; or they can opt for what I will call the "easy street." Easy street is accepting the role that "society doesn't want us to be productive; rather, society would feel better if we were to stay at home—for some, home being public-supported institutions—and collect our welfare checks."

Briefly, let me point out the major flaws of each of these three choices a severely physically handicapped person would have without H.R. 7466:

One, with regard to volunteers at the work site, we are talking about ordinary men and women engaged in their particular occupation, people who would be asked all of a sudden to become involved in a unique and demanding profession requiring special skills that many severely physically handicapped people depend on for living. These skills are such that not everyone would be able or willing to physically, and most importantly, psychologically cope with and handle.

Permit me to elaborate on a few of these skills at this point, because I feel that they will show the special qualities needed in an individual that aren't within all volunteers.

An individual caring for a severely physically disabled person must be able to recognize a crisis condition known as autonomic hyperreflexia, which is usually caused by an enlarged bladder, impacted bowel or a deep infected pressure sore. The individual will show symptoms such as a severe headache, sweating of the forehead, restlessness, extreme anxiety, chills and goose bumps, skin flushing above the lesion and high blood pressure.

Without proper treatment, convulsions, hemorrhaging in the cranial area and even death may occur. The assistant must act quickly to find the cause of the given crisis and work to bring the blood pressure down. However, some of these symptoms may not necessarily indicate the individual is experiencing autonomic hyperreflexia.

Sweating, chills, and goose bumps, for example, may indicate either the presence of a pressure sore—usually in a bony prominence—or the onset of a urinary infection. Either one of these conditions must also have the appropriate medical treatment begun immediately.

An ignored little skin breakdown may very possibly lead to deep, infected sores which, besides loss of work time, might require hospitalization and surgery.

If the personal physician or urologist of the handicapped individual isn't made aware of the beginnings of a urinary tract infection, serious renal complications will undoubtedly ensue. As of now, renal failure is the leading cause of death among severely injured spinal cord individuals.

"Hot flashes" within the disabled individual may indicate the warning stages of a sudden diarrhea attack, in which case, the sooner into bed and prepared, the better. The cleanup of a diarrhea incident must be done in a way so as not to scrape any skin to cause a breakdown. Urinary continence systems are not uncommon sites of breakdowns that the assistant must know how to clean up.

These cleanups require the ability to get the handicapped person into and out of bed safely. These graphic illustrations are good examples of unpleasant realities which personal assistants must have the strength to deal with, both physically and mentally.

The severely physically handicapped person needs to drink plenty of liquids throughout the day, to help keep the urinary system from building up harmful bacteria.

The assistant must also become familiar with the occurrence of sudden muscle spasms which, if strong enough, can knock the individual from his/her wheelchair. The administration of medicine is an important function of the assistant.

The knowledge of the different medications, their proper administration dosage and schedules, as well as the purpose of each medication must be internalized by the assistant.

Such emergencies that come up, along with these daily needs of a severely physically handicapped individual, can occur at all times of the day. Thus, a system of volunteers would not work efficiently to meet these daily demands.

Aside from the physical limitations of a volunteer network, the severely physically handicapped's sense of independence and self-dignity must be a crucial and vital consideration in both realizing that an assistant is needed and in screening these assistants to meet these delicate qualifications for the job.

To rely on a continuous need for asking someone for a favor in the long run will lead to alienation and possible resentment on the part of both the disabled and the office employees around.

Likewise, should an emergency arise or some special task be needed that takes particular skills or physical strength, the volunteer system will ultimately be approaching a game of "Russian roulette" with an individual's life.

My experience in an office setting has shown me that fellow workers have the warmest hearts and utmost willingness to help out with an occasional problem, but their limited abilities to deal with some of these emergencies or daily tasks mentioned above has many a time put the idea of a volunteer network to rest. It even took a few months for a few coworkers to feel comfortable around this handicapped attorney. In this handicapped attorney's office, the attorneys are responsible for processing a certain number of cases in a given period of time. Additional volunteer services to a handicapped employee would interfere substantially with their productivity.

Two, the notion that a severely handicapped employee can hire and pay for his/her own assistant is seriously in error. For when a severely physically handicapped person starts working, they lose their supplemental security income checks, checks that provide for the payment of home care assistants. The idea then, of an employee turning employer without the economic means is the sad but logical result of this dilemma for many.

Three, without the economic means nor the constant physical care required, "easy street" may become the solution by default. Imagine someone telling you that because of a certain difference between yourself and the rest of society, society would feel more at ease if you didn't concern yourself with working or achieving per-

sonal satisfaction and the self-dignity that comes from feeling productive.

Would you, or any other person, feel a sense of worth about yourself and to others with society closeting you up? And, is society willing to spend about \$30,000 a year of its taxed dollars to closet these people?

By now, we can begin to see the dangers of these three choices if a personal assistant weren't allowed to take charge in caring for the special needs of these disabled individuals.

It is with utmost confidence that I can say that H.R. 7466 is a very logical and much needed bill to solve these problems. Thus, H.R. 7466 will not only create a new professional group of individuals within the Federal work force, but it will encourage many severely physically handicapped people to come forward and seek jobs, thus enabling them to feel a purpose and value in their lives, and to live up to the American way of life; that is, enjoying the physical and psychological fruits of hard work.

Finally, a personal assistant position will enable the severely physically handicapped to negate any feelings that he/she is a burden on society—living off free checks rather than working and contributing taxes of their own. This should be an appealing idea to us all—being a breadwinner, not a bread receiver.

Why all of a sudden is H.R. 7466 such an important measure in enabling hundreds of severely handicapped people to seek employment? Well, the answer is that the number of severely physically handicapped people recently able to be kept alive has significantly increased.

Let me try at this point to narrow down the severely physically handicapped people we are dealing with when we talk about H.R. 7466, and give a little descriptive and interesting information on the history of high spinal cord injured.

According to section 7 of the Rehabilitation Act of 1973, severe handicap means:

The disability which requires multiple services over an extended period of time and results from amputation, blindness, cancer, cerebral palsy, cystic fibrosis, deafness, heart disease, hemiplegia, mental retardation, mental illness, multiple sclerosis, muscular dystrophy, neurological disorders (including stroke and epilepsy), paraplegia, quadriplegia and other spinal cord conditions, renal failure, respiratory or pulmonary dysfunction, and any other disability specified by the Secretary in regulations he shall prescribe.

As you read over this list, there are some conditions, such as cancer, heart disease, mental retardation, mental illness, et cetera, that would not pertain to the hiring of personal assistants. Rather, by severely physically handicapped people, we are only talking of those individuals whose physiological functions are so impaired that their normal activities of daily living cannot be performed without the help of a personal assistant.

As an example, in discussing severely physically handicapped individuals, I will use high spinal cord injured individuals—quadriplegics—due to my professional and personal involvement in this field.

The job of keeping spinal cord injured individuals alive and rehabilitating them to lead relatively normal lives is a very new sociomedical field. During World War II, the mortality rate for spinal cord injuries was 80 percent. Since World War II, develop-

ments in physical medicine and rehabilitation have demonstrated that the impact of paraplegia and quadriplegia need not be catastrophic. However, only 20 years ago, few patients with spinal cord injury lived past the age of 40. Today, increased knowledge of spinal cord injury and its complications, and the stepped-up application of this knowledge, mean that quadriplegics in their twenties can look forward to their 60th birthday and beyond.

When medical and paramedical services prove to be successful, vocational rehabilitation becomes a vital element in the total rehabilitation process. Each individual is assessed by a rehabilitation team to determine what physical range of motion the individual has, and how to most effectively use this toward independent living and, ultimately, employment.

These recent breakthroughs have come at a good time. There is widespread opinion that the rate of occurrence of spinal cord injuries producing some degree of functional damage will be at least 20 each year for each million inhabitants. And, according to various studies, the majority of spinal cord injury individuals are males, with the average age below 30.

The basic reason for these figures are the major causes of spinal cord injury: automobile accidents, falls, war, civilian gunshot/knife wounds and sports injuries. What we are talking about, then, is the increasing number, about 10,000 a year, of spinal cord injured individuals, the major of which are young and eager to get on with their lives and enter the work force.

For some—estimated around 20 percent—of these newly spinal cord injured, constant personal and medical assistance is necessary to enable them to enter the work force and to function independently in their work environment. Once again, we hit the snag in the process of full rehabilitation for some—the lack of an assistant position set up to meet the unique needs of these injured. The answer to come out of this Catch-22 dilemma once again is found, partially, in H.R. 7466.

For the past 3 years, besides being a home-care personal and medical assistant for a quadriplegic, I have, as well, been working with him as a legal clerk. We started working at his office together, without anyone at the office really understanding that quadriplegic attorney's needs. Over the past 3 years, we have developed a very real and practical working arrangement, and from this experience with a quadriplegic in an office setting, I once again stress the importance of H.R. 7466's enactment. Most of the office personnel around us, be they management, attorneys or clerical/support staff, have the warmest hearts and utmost willingness to help out if an occasional problem arises, but their limited expertise has many a time put the idea of a volunteer network to rest. It took some of the attorney's coworkers a few months before they even began to feel psychologically comfortable around him. Very few people in the office are able to lift this quadriplegic attorney, a daily medical need, due to insufficient strength or bad backs. For a volunteer system to work, you need the right person at the right time.

Who is to say that in another office or worksite, there would always be that volunteer around to handle a life-threatening emergency? In this handicapped attorney's office, the attorneys are

responsible for processing a certain number of cases in a given period of time. Additional volunteer services to a handicapped employee would interfere substantially with their productivity.

One of the assignments given the handicapped attorney, like the rest of his comrades, is to argue cases before a district or appellate court. If the court is outside Washington, it calls for at least an overnight stay. There would have been no way for this attorney to have argued a case last year in Boston without 24-hour assistance. I am very glad to see that H.R. 7466 deals with this traveling problem by enabling the assistant or someone qualified to travel with the severely handicapped person.

The most important overriding qualities to be considered in hiring and training personal assistants are patience and perception. A severely physically handicapped's life is, for the most part, a much slower-paced one than that to which we fully ambulatory people are accustomed. Personal and medical needs take time out of the normal working day. To be able to constantly care for someone else's needs—and for much of the time above your own—calls for a special kind of person.

Coexisting with patience is the quality of one's ability to perceive another's needs and predicaments before they arise. The ability to plan ahead and be able to put yourself in someone else's shoes is not everyone's forte. If this sounds like a superhuman person is being called for when hiring a personal assistant, to the extent that these intangible qualities of patience and perception are being considered, then the answer is yes. This is why special hiring is mandatory and why recognizing that only through such a provision as H.R. 7466 will such hiring be successfully achieved.

Unfortunately, no one really has an accurate number of how many severely physically handicapped people exist who, while qualified for a given job, do not have the incentive to work without a personal assistant. As I stated earlier, this area of physical rehabilitation is a relatively new sphere of medicine, which like any other scientific breakthrough, the social ramifications cannot be fully felt until a few years later. Such a time is upon us.

In the next few years ahead, much more time and money must be channeled into finding out where all the severely physically handicapped people are, and what they are or aren't doing with their lives, once they are discharged from rehabilitation hospitals. The creation of attendant training and counseling centers will seem necessary to help teach and give continuing support in this unique and most often isolated profession.

Increased tax incentives for private industry could be seen as a way to employ a qualified severely physically disabled individual and a personal assistant, thereby enlarging the scope of employment opportunities for the disabled.

How much money can be saved in the long run by taking the time and efforts now to seek out and employ handicapped people presently on public assistance rolls? Can we afford to let our severely physically handicapped be put in nursing care homes or left in a co-op apartment or anywhere to vegetate, both physically and mentally?

Can we afford to tell a fellow human being to put away his/her dignity and self-esteem from our view because they are a little

different from us? I think not, and I don't think anyone in this room today thinks so. But without such a bill as H.R. 7466, we will continue to do just that for some severely handicapped people.

I would like to end this discussion with a definition of the term "rehabilitation." To "rehabilitate" means to restore to dignity; to reestablish on a firm sound basis; to restore to constructive activity by medical, psychological and physical therapy; to prepare for useful employment by vocational counseling and training.

Rehabilitation does not end at the moment of discharge from the hospital, but rather begins when the person practices the techniques he has learned in the hospital and applies them in coping with his own world. Rehabilitation will not end when a handicapped person seeks and gains employment. No, rehabilitation will not end for them—unless they are told to make it end, for lack of trained personal assistants, a power beyond their control. Would anyone want to accept responsibility for that power—does anyone dare?

Madam Chairperson, members of the subcommittee, I thank each and every one of you for allowing me to share my knowledge, experience and thoughts with you on this significant bill, H.R. 7466. I would be very happy to answer any questions you may have at this time.

Mrs. SCHROEDER. Thank you very much. What an excellent statement. It is very sensitive, and your own personal experience, I think, certainly helps all of us.

You stated very special qualifications are needed for these assistants. Do you feel that skill can be taught? Can you teach people to recognize the conditions that you talked about in your testimony? Who should have that skill? Who should be the one who hires those assistants for the very severely handicapped? Should it be the patient, himself? Obviously personality compatibility is important, too. How would you propose that we look at that?

Mr. COLANGELO. I am speaking not as an expert at all, just as an individual, so I really don't have many answers as to how the mechanics of hiring take place.

Certain skills can be taught. What I was referring to was the patient's perception, psychological dealings with being around and taking care of the needs of somebody else. I don't really think that can be taught. Either people have it or they are not comfortable with that kind of environment.

I think when it comes time to hire a person, a match-up between the severely handicapped and the personal assistant is necessary. It is just like a marriage; if the personalities just don't coincide, divorce is what usually happens.

Mrs. SCHROEDER. Part of what I am asking is, you started your statement by saying you never thought you would be in the position you are in, that an accident, very regrettably, put you in that position. You obviously were trainable to do this. I think probably most Americans never think they will ever be in that situation, be they office workers, family, whatever. In your 3 years of experience working through this volunteer network, do you find a change, as people get more used to this? Are they becoming more comfortable with it?

Mr. COLANGELO. No.

Mrs. SCHROEDER. You do not think so?

Mr. COLANGELO. No. Where I work, there are very few people that can lift this individual up. This person has a history of skin breaking down in the rear end, and constant lifting is necessary. When we first started, I had a bad back and we needed to get a volunteer system every hour to get this person lifted. It ended up half the time the people who were supposed to be ready to come and lift either forgot or had to go somewhere.

We are talking about people that are engaged in their own occupations and to say, well now, you are going to be expected at such-and-such a time is nice, but in reality the chances of something coming up where they can't make it occurs. If there are only a few people qualified to do a certain task and they are not around, you will run into problems.

Mrs. SCHROEDER. I see what you are saying. People didn't understand the importance of it as they were more and more exposed to it.

Mr. COLANGELO. People understand the importance, but understanding and being able to cope with or to be able to handle the situation is not within everybody that understands the importance, from my experience.

Mrs. SCHROEDER. I noticed you also said that a lot of severely handicapped really would be reluctant to enter the Federal service. Do you think the passage of this bill permitting assistants will help?

Mr. COLANGELO. Yes, if they are still within reach to be helped. By that I mean I have worked prior to working in Washington for a quadriplegic going to school in New York. There were a fairly large number of quadriplegics who were going to college there. Most of them were on the 10-to-12-year college route because they knew very well that all their attendant care needs and all their supplemental incomes would be cut off once they tried to get a job. They also realized that if they couldn't get an assistant to help them, they really couldn't function. So they said, I will take one or two courses a semester and just hang out and have fun. That attitude is prevalent there from my experience.

Mrs. SCHROEDER. So there is a disincentive?

Mr. COLANGELO. There is right now. If somebody can say, hey, you have now the means to come to work, you will be provided with an assistant at work, that excuse is not there; what do you say? I think you will see a change in the desires of a lot of people to say now we can do it.

Also, in that regard, in my statement I mentioned this area is very new. The ability to keep somebody alive after a spinal cord injury for more than a few years has been stepped up so much today that it is only now that a lot of people are starting to be noticeable in number, so you are going to find a lot more people in the situation in the coming years ahead.

Mrs. SCHROEDER. I thank you very much for being here and doing such a good job.

The next witness we have this morning is Evan Kemp, Jr., who is the codirector of Disability Rights Center, Inc.

Welcome. We are very happy to have you with us, Mr. Kemp, and we will look forward to what you have to say.

STATEMENT OF EVAN KEMP, CODIRECTOR, DISABILITY
RIGHTS CENTER

Mr. KEMP. My name is Evan Kemp, and I am codirector of the Disability Rights Center. The center was established in 1976, with the help of Ralph Nader. A substantial amount of its work involves monitoring the efforts of the Federal Government on the implementation of affirmative action programs for the employment of disabled persons. We are committed to making the Federal Government a model employer of disabled persons, and we hope that the Government will serve as an example to other employers throughout the country.

The Disability Rights Center fully supports H.R. 7466, which would allow the employment of personal assistants for attendant care for disabled Federal employees both at their regular duty station and while on travel status. As a disabled person who was a Federal employee for 15 years, I wholeheartedly support H.R. 7466, because I know how badly it is needed.

The Federal Government would not consider for a moment housing one of its agencies or departments in a building that did not have bathrooms or water. If the General Services Administration determined that no restaurant or other place to eat was within a reasonable distance of a proposed Federal building, it would see that the building had some eating facilities before Federal employees were assigned to work in the building.

It would be a real brain teaser to attempt to count all the health, safety, legal, and morale problems that would arise if a Federal agency or department were without bathrooms or food or water. Consider the furor caused by Federal employees when the hot water was cut off in Federal buildings several months ago. What would have happened if all the water were cut off?

It is shocking, then, to realize that some severely disabled people qualified to occupy positions in the Federal Government would have no food, water, or use of a bathroom without a personal assistant or attendant, and that there is not now any authority for Federal agencies to hire such persons. Some severely disabled employees might be able to perform two of the three essential functions for themselves, but failure to perform one essential personal service can often be an insurmountable barrier to employment.

I want to emphasize that H.R. 7466 would not require a full-time employee for every severely disabled person who needs a personal assistant or attendant care. In fact, 95 percent of the time it would not be necessary for an agency to hire a person as a personal assistant. The service can be easily arranged by including the necessary or essential needs of the disabled person in the job description of a certain group of employees.

Passage of H.R. 7466 would make legal the informal practices and procedures that many disabled people have used and are still using. The cost of a personal assistant would be minimal. In fact, it would be a good investment. For every Federal tax dollar spent to employ the disabled, the U.S. Treasury gets back \$9. If the Government spent enough to employ the disabled, we would balance the Federal budget.

Passage of H.R. 7466 would signal to the disabled and non-disabled alike that the Federal Government is taking seriously its

expressed commitment to be a model employer of the disabled and that the Federal Government is willing to make all reasonable accommodations that are necessary to allow the severely disabled person to become a productive and taxpaying member of society.

The center appreciates the opportunity you have given us to put our views on the record.

I would like to comment a little on the previous speaker, John Colangelo. I felt it was a very good presentation, though it troubled me a bit. I tend to find that I have had real problems with people who were supposedly trained to give assistant care; volunteers have always been excellent. The only bad experience I had in 15 years with the Government was with a nurse at the agency that I worked. I am absolutely petrified if I ever have to go to a hospital. I know a lot of other severely disabled people who have the same feelings I do about hospitals.

I thought it was a good presentation because I do think there is a tendency to minimize the problems of severely disabled people. For a long time, the Government thought once a person was on board and hired, he was just like everybody else. But a person with a spinal injury does have special problems, and I think that the agency should be aware of them.

But I found that volunteers are best if the person with the severe disability can tell the person what he needs. The person has to have that confidence to be able to tell his needs, but I much prefer volunteer assistance to so-called trained assistance.

Mrs. SCHROEDER. I take it from your testimony that what you are saying is from your experience, a lot of the personal assistance needed can be given by your coworkers. Is that what you are saying?

Mr. KEMP. Yes.

Mrs. SCHROEDER. You didn't need somebody sitting next to your desk, but obviously it is a different situation with a person with a spinal injury.

Mr. KEMP. I have known a lot of people with spinal injuries and, of course, it depends on the injury, but I think a great many of them would not need a person sitting beside them. Ninety-five percent would not. Water can be a problem, eating, going to the bathroom, but this doesn't occupy 8 hours of every day and getting to and from the car.

I think people with severe disabilities don't maximize the number of times they go to the bathroom or drink water. Their eating habits are simple. You don't need constant attention. In fact, I wouldn't want it.

Mrs. SCHROEDER. Maybe that is the hardest problem we have under this bill. I hope it passes, and I hope we make a beginning in sensitizing managers to the very wide range of different kinds of skills needed to give them the flexibility to deal with it. If you are blind, clearly you need a reader. If you are deaf, you will need an interpreter. There may be a lot of things the coworkers can do if they understand the problem. There may be some things, such as spinal injuries, that call for education and training. There is no magic formula for finding one person that can take care of all this.

Mr. KEMP. I do think the person with the disability has to express what he needs. There are certain things that can come up

infrequently where another person might see an emergency occurring, but the person with the disability can't express his needs. I think it is very important that the disabled person be consulted and asked what he needs to be a good employee.

Mrs. SCHROEDER. Have you ideas for other things the Federal Government can do to help increase the hiring of the disabled?

Mr. KEMP. I think EEOC, with its goals and timetables, is a step forward. I think the more employees you have with disabilities, the more you break down the attitudinal problems. I think it is unfortunate EEOC—the section concerned with the disabled—is being sent out to Bailey's Crossroads. It is a long way from the people.

Mrs. SCHROEDER. I know. I live there. It is a long way to drive.

Mr. KEMP. I think that is a problem.

I think also private employers are doing quite a good job and they are doing it because they have tax incentives. I have always thought Federal agencies should be given some sort of bonus if they do a good job of hiring disabled people that would be outside of appropriations they normally receive, and that would be administered by a committee in Congress that is concerned with disability problems. As an ex-Federal employee, I know how important money is to Government agencies. If a Federal agency does a good job, why not give that agency extra money and maybe it will come up with new and innovative things to do? It has worked in the private sector.

Mrs. SCHROEDER. That is interesting. I thank you again, Mr. Kemp, for being here. We really appreciate your statement, and help us with the bill.

[The additional statement, which follows, was received for the record:]

REBUTTAL STATEMENT OF JOHN COLANGELO, REGARDING COMMENTS MADE BY MR. EVAN KEMP, CODIRECTOR OF DISABILITY RIGHTS CENTER

This statement is presented to the subcommittee in reference to remarks made by Mr. Evan Kemp at the August 20, 1980, hearings on H.R. 7466. I can truly feel for Mr. Kemp in his dealings with scarey, unreliable and probably very incompetent assistants and hiring agencies you have had to deal with. I too, through my dealings in this area of rehabilitative medicine, have seen too many inept people who claim to pass themselves off as trained, professional assistants. The handicapped person, unfortunately, ends up as being very distrustful of any assistant they employ, and rightly so. But the answer is not to do away with the idea of a trained professional assistant, but rather to make the health care industry aware of this grave problem and coordinate a system whereby assistants who claim to be trained are in fact qualified to handle the various needs and emergencies of a severely physically handicapped person.

Training a person for some of the necessary physical skills can be done, as I have indicated in my testimony. However, certain personality traits essential to a person working with severely physically handicapped people cannot be taught, but need to be recognized as a part of the hiring process at a work site or attendant care agency or whatever the particular agency/institution may be. It is very sad to say, albeit true, that most agencies never take a good look at the makeup of a potential attendant, nor do they seem to have a follow-up system whereby the agency/institution makes sure the handicapped person and attendant are compatible and the attendant competent. Thus, many "incompetents" are incorporated into the ranks of attendant care workers, and worse, some bearing personalities geared towards seeking power over another; others finding an outlet for their sadistic tendencies.

I, too, have a lot of trouble with many so-called trained assistants. But if agencies do not care whom they hire (by not screening and training potential assistants), is it not a wonder that such incompetent people assume many necessary life-dependent tasks. As a good illustration of this point, let me relate to this subcommittee the

following true episode. While working as an attendant up in New York several years ago, curiosity overtook me and led me into a well known nursing/homemaker-home health aide agency. Not indicating any previous experience about my dealings with handicapped people, I simply asked the person there for a job working with disabled people. I was asked to fill out a form which only included such queries as to my age, sex, phone number, what days and shift I'd be willing to work, etc. When handling the form in, I asked what next. They told me that they'd try and find someone who needed an attendant to accommodate my hours. I then asked about training to be given me, and they told me not to worry about it. It was that easy—just walk off the street and sign up. And I would have been classified as a trained professional assistant. Perhaps if this area of rehabilitative medicine were given a little more attention by rehabilitation agencies and institutes, better ways could be looked into selecting, training and assessing those individuals wishing to be employed as medical and personal assistants.

Mr. Kemp has also raised the question of volunteer assistance as opposed to trained assistance. It is true that for each disabled person, methods and ways of achieving desired results vary totally. It should be up to each handicapped person to explain his/her particular need and habits and personal likes and dislikes, etc. to a personnel department where he/she is to be employed. However, it should not be the handicapped's role to teach each and every skill that can be taught to an assistant. As I said in my statement, aside from the physical limitations of a volunteer network, the severely physically handicapped's sense of independence and self-dignity must be a vital consideration in realizing the necessity of an assistant. There are those severely disabled persons who do need constant assistance throughout the working day, assistance beyond some disabled' much simpler needs of getting into and out of a car, feeding, and providing drinks. If a disabled person wants to keep his association with his co-workers as strictly professional as possible, there would be no better way to do just the opposite than continually asking for a favor. I have observed different reactions to a situation from the same totally severely physically handicapped individual. When an assistant that was working for them was present, the disabled person would think nothing of asking for a glass of water or scratching part of their face, or holding up a section of the paper. However, while the assistant was away for a length of time and friends or co-workers were around, the same glass of water wasn't so readily asked for; the itch in the face not that discomforting to have it scratched. We are dealing with human beings with different psychological makeups. If we should expect every severely physically handicapped person to be able to continually ask co-workers for favors and the physical necessities in their job-related duties, can we realistically expect a totally disabled individual to feel a true sense of independence?

Finally, let me point out that this bill, along with helping those severely disabled individuals already employed in the Federal government, will be significantly helping a "growing minority" of our severely physically disabled citizens. These individuals cannot perform any physical tasks or cannot take care of any activities-of-daily-living without continuous assistance. We are talking obviously about more help required to get through a working day than just helping a person into and out of a car and helping a person perform "1 out of 3 essential functions necessary to seek employment." Perhaps Mr. Kemp, my statement has been geared towards this "5 percent minority" of those severely physically disabled people in need of constant care, and rightly so, because this has been the center of my dealings with physically handicapped people for the past five years. Treating this bill, H.R. 7466, as a bill that will not require constant eight hour-a-day assistants, for the most part is true. But should we decide to make H.R. 7466 a bill for all severely physically handicapped individuals, that "minority 5 percent" will not be able to work with the conditions governing the other 95 percent's needs. To look at how this bill will affect those severely physically handicapped individuals employed by the Federal government already, without taking a look at the tremendous potential for those "5 percent" unable to realistically function at a jobsite now, is not the basis for intelligent future planning and development of some of America's "untapped resources." Likewise, H.R. 7466 should be implemented from the perspective of meeting these very severely physically handicapped's needs as the bill's foundation not as an after-thought for a few individuals that need the most care.

Mrs. SCHROEDER. The next witness we have this morning is Leslie Milk, who is the executive director of Mainstream, Inc. Leslie, we welcome you and look forward to your testimony.

**STATEMENT OF LESLIE MILK, EXECUTIVE DIRECTOR,
MAINSTREAM, INC.**

Ms. MILK. Thank you.

Mrs. Schroeder, members of the committee, and friends, I am pleased to have this opportunity to testify today concerning H.R. 7466, a bill to amend section 3102 of title 5, United States Code, and section 7 of the Federal Advisory Committee Act to permit the employment of personal assistants for handicapped Federal employees both at their regular duty station and while on travel status.

The United Negro College Fund said it best—"A mind is a terrible thing to waste." But this Nation, and the Government which represents it, is still in the business of wasting minds. We waste these minds because the people who have them and the talents that go along with them lack other skills—the ability to see, hear, write, walk. Mainstream, Inc. supports H.R. 7466 because it offers an opportunity for the Federal Government to utilize the talents of qualified handicapped people, by providing the personal assistance needed by these people to do jobs they are willing and able to do.

We believe that this bill will do more than bypass the barriers of budget and slots which currently keep many handicapped individuals from entering the Federal work force. It will raise the consciousness of Federal managers about the capabilities of severely disabled people to function effectively, when the accommodation they need is provided. The fact that this awareness is still absent at the highest levels of Government was recently made painfully clear by the experience of Mainstream's founder and legal counselor, Harold Krents. Mr. Krents is the blind lawyer whose experiences inspired the Broadway play and movie, "Butterflies Are Free." In addition, his own autobiography, "To Race The Wind," was the subject of a CBS television movie last season.

To briefly state Mr. Krents' credentials is not an easy task. He is a graduate of both Harvard College and Harvard Law School, with an advanced degree from University College at Oxford, and has been engaged in the practice of law in Washington with the firm of Surrey & Morse for the past 8 years. Mr. Krents was recently selected as a White House fellow for 1980-81.

He rightfully expected that a number of Federal agencies would be eager to avail themselves of his services. This was not the case. In the White House itself, and in several Cabinet Departments, the reaction to the prospect of a blind White House fellow was blindness—blindness to the possibility that a highly qualified blind lawyer could do the job. The possibility of accommodation—the provision of a reader—which had enabled Mr. Krents to function as a successful attorney in private practice, was not considered by many who interviewed Mr. Krents. Over and over again, he heard many of the responses which he had heard at his college interviews and his law school interviews and his first job interviews, "My God, you're blind. You won't be able to handle the paperwork."

The irony for Harold Krents was that for the past 5 years his energies have been devoted to advising private sector employers on their responsibilities under law for accommodating handicapped workers. He found the private sector far more knowledgeable and far more willing than the public sector.

For Harold Krents the story has a happy ending. Fortunately, there are agencies and offices where the message has gotten through that qualified disabled people can offer much if they are accommodated. Hal Krents will begin his term as a fellow in September and provision has been made for a reader for him. But we will never know how many stories ended far less happily, both for the handicapped individual and for the Government which desperately needs talented and creative people.

Having recounted one near-failure, let me tell you one possible success story. The new Director of Litigation for the Office for Civil Rights in the Department of Education is John Jay Dystel, an attorney who has multiple sclerosis. It was understood by the department from the outset that Mr. Dystel would need a reader, since his handicapping condition affects his vision. In addition, Mr. Dystel uses a wheelchair and cannot travel without a personal assistant. This, too, has been promised. But you also need to know, to put it bluntly, what the Department of Education got to make the accommodation worthwhile.

The new Director of Litigation is a graduate of Brown University with honors and the Yale Law School. He served as an assistant to Nicholas Johnson when he was chairman of the Federal Communications Commission, clerked for Judge Alfred T. Goodwin at the U.S. Court of Appeals for the Ninth Circuit, and was a founding partner in the law firm of Wickwire, Lewis, Goldmark, Dystel and Schorr in Seattle, specializing in litigation. In addition, he served as the director of advocacy for the American Coalition of Citizens with Disabilities.

John Dystel, as of yesterday, was still expecting his accommodation. He has been on the job for nearly 2 months. But the Department of Education is a new agency and we are therefore awarding them a certain period of grace.

We know accommodations are possible. At the Securities and Exchange Commission, for example, a number of blind attorneys have been accommodated with legal technicians who serve as readers and with temporary readers to fill in any gaps.

What should matter is not the vision of Harold Krents or John Dystel, or others like them, but the vision of the Federal Government in making use of their considerable talents and expertise. We believe that H.R. 7466 is an important step in increasing the ability of the Federal Government to see and to use the talents of disabled people and to set the example for the private sector as well.

I would like to add a couple of notes. One is that I think the importance of it will not be what goes into the legislation, but what happens after it is passed. Who looks to see whether, in fact, these accommodations are not possible but are, in fact, taking place?

Personnel ceilings are very often used as a reason for not doing it. I think when you force a disabled person to justify a 2 for 1 trade, they would have to be like the fullback of the Oilers to make that possible. It is a terrible burden on the agency. It is also a burden on a handicapped person, particularly one who is just starting out and doesn't have a four-page résumé to justify employment. That is why it is very important. I understand about tight budgets, but I wonder—if we can't up the money, we can certainly waive

the personnel ceilings if agencies can find it in the budget, so that these people do not have to be hired on a 2 for 1 basis.

I also think this is a very timely bill considering we are going in on this International Year of Disabled Persons. Mainstream, as many other organizations, is terribly afraid that IYDP is going to be a lot of parades and proclamations and nothing to celebrate. Perhaps this bill can be somewhat of a way of getting the Government to do more during IYDP.

Mrs. SCHROEDER. Thank you very much. It is certainly our hope that the bill knocks away excuses. We clearly will be looking to see what the performance is. If there is no performance, then all of this is a waste of time.

I really appreciate your testimony. I think probably both of us marvel at the strength of people who are able to take all that rejection and still keep hanging in there. Particularly for those who are not quite that strong in ego strength and security it is hard to take that kind of rejection. I thank Mainstream for all it has been doing. Help us with our bill.

Our next witness is Sharon Wilkin, of the National Spinal Cord Injury Foundation.

STATEMENT OF SHARON H. WILKIN, NATIONAL SPINAL CORD INJURY FOUNDATION

Ms. WILKIN. I wish to begin by thanking you for the opportunity to testify today in support of H.R. 7466, a bill to permit employment of personal assistants for handicapped Federal employees and handicapped members, staffs, and consultants of Federal advisory committees. I am Sharon H. Wilkin, a member of the board of directors of the National Spinal Cord Injury Foundation.

Established in 1948, the foundation has chapters in 60 cities and speaks for approximately 200,000 individuals in the United States who live with some degree of spinal cord impairment. About half are quadriplegics, that is, persons whose arms and hands are paralyzed. Many of these quadriplegics need some form of personal assistance in order to be employed.

Mrs. SCHROEDER. I am sorry. We will have to take a temporary recess.

[Brief recess.]

Mrs. SCHROEDER. Thank you. I am sorry for the interruption. Please proceed.

Ms. WILKIN. Approximately 11,000 new cases of spinal cord injury occur each year. Eighty percent of the persons affected are under 40 years of age. Most people who injure their spinal cords are either working or attending school as full-time students when it happens. However, 3 years after injury, fewer than one in five quadriplegics is employed. One reason is that it is next to impossible to obtain and pay for personal assistance at work.

Section 3102 of the Civil Service Reform Act of 1978 allows the Federal Government to employ reading assistants for blind employees and sign language interpreters for deaf employees. It was an oversight not to have included personal assistants for severely handicapped employees with other types of disabilities.

For the most part, the individuals who have been left out are those who are limited in use of their arms and hands. This means

individuals with significant paralysis, weakness, or incoordination of the upper extremities. Some of these persons are spinal cord injured; some have disabilities such as cerebral palsy, multiple sclerosis, and muscular dystrophy. Such disabilities can co-exist with substantial capacity to work productively. But the persons involved are dependent upon personal assistance. They cannot get through a day without the help of another human being.

The Federal Government is required as an employer to make reasonable accommodation to the disabilities of handicapped persons who are qualified for Federal employment. Passage and enactment of H.R. 7466 will make it possible for handicapped persons already employed by the Federal Government to function more efficiently and productively and also will encourage severely handicapped persons not now in the work force to seek and obtain Federal jobs—jobs for which they are qualified now—jobs they cannot have now because necessary assistance is not available.

In recent years severely disabled individuals have had greater opportunities than ever before to obtain education and training for employment. Many leave school with advanced degrees that qualify them for professional careers; others complete vocational training that equips them with skills that are theoretically marketable. But what happens to the person who is "job-ready"—that is, willing and able to do a job—if the person needs assistance in order to work? I am referring to the person: who needs help with a coat and hat; who needs help using the bathroom or eating; whose hair must be combed or whose face or hands must be washed during the working day; who needs help changing position in a wheelchair or getting in and out of the chair for a rest period; who needs someone else to arrange papers, folders, and books; who must depend upon another person to take notes from time to time or to perform other manual writing chores; who must ask other people to place telephone calls or assist with operation of office equipment; who needs to be escorted to meetings or training sessions so that someone will be available to carry a briefcase, set up a tape recorder, write on the blackboard, or turn pages.

These are persons whose physical inability to manipulate the environment very often prevents them from working and earning the money they need to be taxpayers instead of recipients of public assistance. These are persons who are likely to be underemployed when they do find jobs because personal assistance is so difficult to arrange.

Disabled people who need assistance in the work place are routinely turned away when they apply for jobs. Interviewers cannot imagine how these individuals will function. There is no established mechanism to enable development of a reasonable support system. The first and final thought of most Federal managers is that there is no authorization to provide personal assistance, no policy to cite, and no guidance to follow.

A few fortunate persons are employed by the Federal Government in spite of very severe disabilities that necessitate assistance of the type we are talking about today. These persons are fortunate because supervisors and managers in their agencies have been committed enough and innovative enough to find ways of arranging for a service here and a service there so that a satisfactory—if

shaky—support system is created. Other handicapped persons have not been so fortunate.

It is not always satisfactory to depend upon the good will of coworkers. Personal assistance should not be regarded as a favor; it should be provided as a support service that is no more extraordinary and no more dependent upon good will than clerical help is for nondisabled workers. It is not fair to disabled employees or to the persons who work with them for the needs I have mentioned to intrude upon professional relationships. It is even less fair when a disabled individual's career becomes in a very real way dependent upon a coworker's mercy. The disabled individual who must negotiate for indispensable assistance on the basis of being nice enough to deserve it is not free to succeed or fail in the workplace on the basis of job-related attributes. Instead, personal needs control options in a way that is totally inappropriate.

The proposed legislation will permit uncomplicated, straightforward employment and assignment of assistants. This will make it easier for persons with severe physical handicaps to hold positions commensurate with their qualifications and to realize the career potential that is now being wasted in many cases.

I wish to emphasize that most of the people we are talking about need less than an hour of assistance each day. Recent technological advances enable many persons who are very disabled to function largely independently. There are, for example, speaker telephones, adapted dictating machines, electric page turners, power wheelchairs, and countless custom-made devices that permit performance of various tasks with minimal physical exertion. Although equipment cannot entirely substitute for help from another human being, it can minimize the amount of assistance required.

The problem is that assistance usually is needed for only 1 to 5 minutes at a time. It is therefore impossible to pay someone to do what is necessary, for example, from 1 to 2 in the afternoon. This means that it would be prohibitively expensive for a handicapped employee to hire a person who is not a Federal employee to come to a Federal work place and provide assistance. Members of the Federal work force, however, could be used efficiently and inexpensively for this purpose. In most cases, payroll costs would not increase at all.

Present employees of the Government can be made available for the short periods of time required with so little effect on workloads that employment of additional personnel would be rare, though occasionally it would be necessary. The proposed legislation provides flexibility in this regard. When agencies do choose to hire individuals specifically for the purpose of providing personal assistance, it is likely that the cost will be small for one or more of the following reasons:

The person will provide services to a large enough number of handicapped employees so that the cost per employee will be minimal; the person will be a part-time employee; the person will devote most of his or her time to duties other than personal assistance, duties that someone would be paid to perform anyway.

Please understand that the type of assistance needed is nontechnical in nature. Only in the most exceptional circumstances would it be desirable for the individual providing services to be profes-

sionally trained. It should be noted, however, that nurses already are available to Federal employees through Federal health units, and in some instances these nurses would be excellent and readily available sources of assistance. The proposed legislation would authorize appropriate assignments.

An important aspect of H.R. 7466 is authorization to pay for assistance associated with travel. At the present time, expenses must be borne by the handicapped employee, or travel is out. This is true even though the Federal Government spends more travel money per year on many of its employees than would be required in most cases to allow a disabled person to make a year's worth of essential trips with the expense of personal assistance paid.

An individual who is unable to travel—ever—is severely limited in career prospects and in ability to serve the Federal Government. On the other hand, most Federal jobs do not involve extensive travel. Persons with severe physical disabilities will be able to hold these jobs, if travel allowances cover the cost of personal assistance.

Like assistance at the worksite, assistance elsewhere often can be the responsibility of persons who are already employed by the Federal Government. Possibilities include Federal employees who work in the city of destination and Federal employees who have job-related reasons to make the same trip the disabled employee needs to make. One of these alternatives may be as satisfactory as, and less expensive than, hiring someone at a distant location. Sometimes it will be necessary and cost-effective for a handicapped traveler to be accompanied by a personal assistant; sometimes it will not. The proposed legislation would provide the flexibility needed to minimize costs and nevertheless allow the Government to make full use of the available knowledge, skill, and ability of its severely disabled employees.

Among other things, the proposed legislation would put an end to an ironic situation Federal agencies now confront. Certain advisory committees are mandated to address problems related to rehabilitation, disability, and employment of handicapped individuals; however, these committees often cannot obtain the participation of handicapped individuals—who are better qualified than anyone else to assist the committee's work—because it is impossible to pay travel and other expenses associated with personal assistance.

Handicapped individuals possess many different kinds of expertise. Subject areas are not limited to those related to disability. The persons who serve on Federal advisory committees should be the persons who have the type of knowledge these committees need. A nominee's dependence upon personal assistance should not be a consideration—and will not be, if the proposed legislation is passed.

What we need now is to formalize and clearly legitimize provision of assistance for all handicapped individuals who are qualified for Federal employment and whose potential contribution to accomplishment of a Federal agency's mission justifies accommodation of a disability. At the present time, it is easy to hire some people, but not others. I am sure you are aware that blind and deaf persons worked for the Federal Government long before it was possible to employ or assign readers and interpreters. But there were problems and injustices. Now, because of the Civil Service

Reform Act, it is easier for blind and deaf persons to be employed. Supervisors and managers have a better attitude toward the accommodations upon which these individuals depend. We need to make the Federal personnel system work as well for individuals with severe physical disabilities as it now does for individuals who are blind or deaf.

The proposed legislation will not cost; it will pay. Expenditures will be miniscule in comparison to savings achieved by putting people to work who presently are unemployed and therefore are receiving services and payments that deplete State and Federal Treasuries. Expenditures also will be offset by the increased productivity and independence of individuals who are now underemployed.

I have focused on persons with disabilities that affect the upper extremities. It should be noted that the proposed legislation also would benefit a group of handicapped individuals who are more difficult to classify. These are persons other than those who are blind or deaf who nonetheless have need for a reader or an interpreter or a similar type of personal assistant.

An example would be an individual with such a severe speech disorder that someone else must talk for the person, much as a sign language interpreter may speak for a deaf individual, who use sign language to tell the interpreter what to say. Presently a deaf person could have this type of assistance, but a person with another disability could not. A similar inequity would occur if a handicapped individual who was not blind required a reading assistant. For example, some persons with cerebral palsy experience so much spasticity that they cannot focus on the printed word well enough to read efficiently, even though nothing is wrong with their vision. Presently it would not be permissible to employ a reading assistant in such a case, although it would be permissible if the person were blind.

Experience has taught that employment of blind and deaf persons is a good investment of Federal funds. It is no less likely that employment of persons with other severe disabilities also will be a good investment. Physical inability, no matter how severe, does not preclude the possibility of working hard and working well. Our experience with Federal employment of handicapped individuals demonstrates beyond a doubt that extended efforts and liberalized authorities are justified and will be productive.

The rationale is practical as well as moral. Not only does the Federal Government have an obligation to provide equal employment opportunity and to take affirmative action, the Federal Government also has an obligation to put an end to unnecessary expenditures of public funds. It is absurd to spend the taxpayers' money on handicapped individuals who are idle when they could be—and want to be—working.

Today, a majority of disabled adults of working age are not employed. Among those who are, earnings average half those of nondisabled workers. This is a situation we cannot afford. By passing H.R. 7466, you, as lawmakers, can take action to change these statistics for the better. Every taxpayer will benefit, not only our spinal cord injured citizens, not only our handicapped citizens. Our country, and in particular our economy, will be strengthened.

Mrs. SCHROEDER. Thank you very much. I really want to compliment you on your testimony. You did a lot of work on that.

I think since the bill directs and gives permission for the Federal Government to hire the personal assistants we have been talking about that are so essential, I want to expand a bit on what you were saying in your testimony. You were saying it is not fair—and I think you are right—for someone who is disabled to have to rely on the person next to him to help him with his career.

For these personal assistants, would you have them be outside of that labor pool, or would you offer—maybe if someone wants to be alongside and help, they should get extra pay. Have you given any thought to how we allow that to happen?

Ms. WILKIN. I think there are different ways, depending on the needs of a particular job and the disabling condition that the employee has. I guess, for the most part, I am thinking, for instance, with a clerical position you could write into the Federal description that part of the duties is to give certain assistance to a disabled employee so that the person understands when he or she takes that job, it is just part of the job.

Also, I did want to emphasize to try to make it clear that in most instances the help required is very minimal. It may just be getting your coat off after you get to the office. Maybe you can function until lunchtime where you might need help with eating. If someone understands this is part of his job, to help the person rather than being at the mercy of just being nice to you.

Mrs. SCHROEDER. And it is best to have one person assigned to do that.

Ms. WILKIN. If possible—with some backup.

Mrs. SCHROEDER. So you would advise the subcommittee if the bill passes, to make sure that the regulations have maximum flexibility so that could be worked out.

Ms. WILKIN. Yes. Disabilities run such a gamut of severity.

Mrs. SCHROEDER. For us to sit here and decide the way for every manager to go would be inappropriate.

Ms. WILKIN. Yes. I think if you had an informal panel discussion of disabled people who are here at this hearing, I think you would find they have just a wide range of needs. Also, people cope very differently with identical disabilities, too.

Mrs. SCHROEDER. I thank you very much. I appreciate your doing this.

We are going to keep the hearing record open until September 1, so if any of you think of additional statements, let us know. We will try to move the bill so we can get it going after that. Remember, September 1, we will close the hearing record, so if one has any ideas or guidance—we admit we need all the guidance we can get—we would be glad to have it.

With that, we adjourn the hearing. We appreciate your patience and forbearance.

[Whereupon, at 12:15 p.m., the subcommittee adjourned, to reconvene subject to the call of the Chair.]

[The following statements were received for inclusion in the hearing record:]

U.S. DEPARTMENT OF LABOR

OFFICE OF THE SECRETARY
WASHINGTON, D.C.
20210

AUG 26 1960

Honorable Patricia Schroeder
Chairwoman
Civil Service Subcommittee
Committee on Post Office
and Civil Service
U.S. House of Representatives
Washington, D.C. 20515

Dear Madam Chairwoman:

We would like to take this opportunity to urge favorable consideration of H.R. 7466, a bill "To amend Section 3102 of title 5, United States Code and section 7 of the Advisory Committee Act to permit the employment of personal assistants for handicapped Federal employees both at their regular duty station and while on travel status."

Under existing law agencies are authorized to employ or assign employees to assist handicapped employees, but only as readers for the blind and interpreters for the deaf. This bill would authorize the employment of personal assistants for all handicapped employees requiring such assistants regardless of the nature of the handicap.

The Department of Labor strongly supports enactment of H.R. 7466. We believe its enactment would increase the effectiveness of efforts to employ and advance in employment handicapped individuals in the Federal service. The success of these efforts is of critical importance for handicapped individuals, for it is through gainful employment that they can attain independence and self-fulfillment.

The Office of Management and Budget advises that there is no objection to the submission of this report and that enactment of H.R. 7466 would be consistent with the Administration's objective.

Sincerely,

Ray Marshall
Secretary of Labor

KENNETH T. LYONS
NATIONAL PRESIDENT

The National Association of Government Employees (NAGE) welcomes this opportunity to give our full endorsement to H.R. 7466, a bill which would authorize the employment of personal assistants for handicapped federal employees.

Section 501 of the Rehabilitation Act of 1973 (29 USC §791) clearly establishes Congress' intent that the federal government be a model employer of handicapped individuals. Under this section, each department and agency in the executive branch is required to develop an affirmative action plan for the hiring, placement, and advancement of handicapped persons. These plans, which are reviewed and updated annually, are to address the means of meeting the special needs of handicapped employees. In addition, section 2301(b)(2) of the Civil Service Reform Act of 1978 [(5 USC §2301(b)(2))] firmly states that one of the merit system principles our government will function under is providing fair and equitable treatment in all aspects of personnel management without regard to handicapping condition.

If this merit system principle and the Rehabilitation Act of 1973 are to be meaningful, some means of providing reliable and, when necessary, professional personal assistance to handicapped employees is essential. Sufficient accommodation does not mean requiring that handicapped employees depend on the goodwill and favors of co-workers for assistance in manipulating their work environment as is currently the case. Neither does sufficient accommodation constitute requiring employees to pay, from their own pockets, for assistance when travelling on official business. The cooperation of managers and co-workers, in addition to federal non-discrimination policy has enabled many handicapped persons to enter the federal workforce. In fact, 6.4 percent of civil servants are handicapped. However, far more could and should be done to aid this population to fully realize their work potential. Further, far more could and should be done to make civil service a viable option for the countless handicapped people who, because of the difficulties currently involved in functioning in a work environment, have been discouraged from seeking employment.

Section 302 of the Civil Service Reform Act of 1978 (5 USC 3120) took a step in the right direction by providing for the employment

of readers and interpreters for blind and deaf employees. By passing H.R. 7466, Congress would be taking the next logical step in realizing the intention of the Rehabilitation Act and the Civil Service Reform Act. H.R. 7466 would create parity in the level of assistance provided handicapped employees by allowing paralyzed and other physically encumbered individuals to acquire personal assistance similar to that currently available to blind and deaf employees.

The enactment of this measure would mean that various federal employees could be assigned the duty of assisting handicapped employees with such things as maneuvering about the workplace; handling papers, files, books, phones, audio-visual equipment and other objects essential to carrying out duties; and personal grooming and health needs. Under this measure, when current employees are not available to perform such tasks, or are not sufficiently trained to carry them out, professional assistants could be hired. In addition, it will be possible to hire personal assistants for handicapped employees, including members of Federal Advisory Committees, travelling on official business. This is particularly important because the inability to travel, even a few times a year, can be a significant block to career advancement and hence full utilization of skills.

Certainly this measure entails some expense. However, in NAGE's view, any costs incurred will be more than offset by the combined effects of the legislation. H.R. 7466 will increase the productivity and efficiency of handicapped employees. It will bring individuals who are now dependent on the largess of our welfare system into the status of self supporting taxpaying civil servants. And, through a ripple effect, hopefully will lead to similar results in the private sector.

However, cost benefits are not the over riding justification for this bill. The Rehabilitation Act of 1973 established a national policy designed to facilitate the full participation of handicapped employees in our society. If our federal government is to carry out its mandated role of providing a model for the employment of handicapped persons, if this country is to make good on its intention to encourage handicapped people to become fully productive, self sufficient and dignified individuals, H.R. 7466 must be enacted.

COMMENTS OF
FRANK R. DEGEORGE, NATIONAL ADVOCACY DIRECTOR
PARALYZED VETERANS OF AMERICA

The Paralyzed Veterans of America is pleased to submit the following comments to H.R. 7466 as a proposed amendment to Section 3102, Title V, United States Code, and Section 7 of the Federal Advisory Committee Act, which will permit the employment of personal assistants for handicapped federal employees at their regular duty stations, and while on travel status.

The Paralyzed Veterans of America (PVA), a national organization chartered by the U.S. Congress, represents approximately 11,000 veterans of the U.S. Armed Services who have suffered injuries or diseases of the spinal cord, whether service-connected or non-service-connected in origin. All of PVA's members are totally and permanently disabled and without question, are eligible for the provisions included in Section 504 of Title V, of the Rehabilitation Act of 1973, as amended (P.L. 93-112). This section provides non-discrimination in federally funded and/or federally assisted programs.

The personal experiences of some PVA members who are, or have been federal employees reflect the need for support services in the form of personal assistants. However, in the event a handicapped individual truly needs this type of assistance, a written statement from a certified physician certifying the person as handicapped should be obtained. A Doctor of Rehabilitative Medicine, or a physician in the field of orthopedics, neurology or internal medicine could professionally evaluate the handicapped person's need for such services.

While PVA is supportive of H.R. 7466, we also recognize that those persons who will perform the task of "Personal Assistants" must be trained, qualified and certified to perform the services required by the handicapped employee. Sensitivity training must be provided for "personal attendants" to enhance their attitudes and awareness of the needs of the disabled individual.

The following Federal Agencies have promulgated regulations that implement Section 504 of Title V of the Rehabilitation Act of 1973 as amended. These

regulations also include a definition of a handicap:

Department of Health and Human Services
 Department of Education
 Small Business Administration
 Department of Energy
 Department of Justice
 Legal Services Corporation
 Nuclear Regulatory Commission
 Department of Transportation
 National Endowment for the Arts
 Tennessee Valley Authority
 ACTION (Agency combining Vista, Peace Corps, etc)

However, more importantly, no Federal Agency has promulgated regulations that propose to implement Section 501 of Title V of Public Law 93-112. PVA regards this fact as a willful and shameful failure of this Administration's promise to implement the provisions of the Rehabilitation Act on behalf of the nation's disabled veterans and civilians.

The President proclaimed his intention to complete the job of writing these regulations, and signing them, during the 1976 Presidential Campaign, at the Opening Ceremony of the 1977 White House Conference on Handicapped Individuals, and at the May 1980 Annual Meeting of the President's Committee on Employment of the Handicapped.

However, after three years, PVA can only state at this time that we have heard the President cry "wolf" once too often. His rhetoric is not borne out by his performance on-the-job. The simple fact is that in his pathetic attempts to have the Federal Agencies and Departments implement Title V regulations, President Carter has failed abysmally.

PVA thanks the Subcommittee on Civil Service for the invitation and opportunity to present our comments. Please find attachments and support studies to our comments which were previously prepared by the Paralyzed Veterans of America.

PVA Aide and Attendance Survey (1975)

INTRODUCTION

This survey was undertaken to determine a realistic cost of aid and attendance for the severely disabled veteran, the veteran who must rely upon the service of others in order to remain free from an institutional environment.

The philosophy which guided this gathering of data is that aid and attendance is paid in order to alleviate the financial burden placed upon the catastrophically disabled veteran as a result of sums of money paid for services required because of the veteran's unique medical and physical situation. As long as such expenses are not adequately met by aid and attendance payments, the veteran's life style is unduly suppressed or his physical health becomes subject to neglect.

Of course, the specific needs associated with different types of disabilities vary. Also, among veterans with similar physical losses, the specific needs for aid and attendance will vary according to the activities of the individual. Because of the complexity of efforts which would be associated with individual determination of aid and attendance needs, this survey centered on costs which would undoubtedly be incurred by a paralyzed veteran who has only limited functions of his extremities and, as most paralyzed veterans, loss of bowel and bladder control. The assumption is that such a veteran desires to live independently of institutional and charitable efforts.

A further assumption is that the paralyzed veteran described above does not want to become a physical or financial burden upon his family, relatives or neighbors. The services in the following paragraphs are based on essential services required for the veteran's well being and physical health.

SERVICES REQUIRED

Although a paralyzed veteran with maximum hospital benefits and a stable condition does not require the attention of a licensed nurse, certain physical aspects of the veteran's care require that an aide has at least some medical training. The services are defined below:

Physical Therapy or Exercise: Most paralyzed veterans require some type of range of motion exercises to keep their paralyzed extremities from contracting or becoming rigid. Such exercises also aid blood circulation and help reduce the possibility of skin ulcers. Also there is evidence that good muscle tone in the lower extremities helps reduce heart fatigue. Thus passive exercises are an essential part of the paralyzed veteran's health care.

Personal Care: Many paralyzed veterans cannot comb their hair, shave, dress themselves or eat without assistance. Also they must be helped from the bed to their chair and back. Thus personal care services involve those activities which help the paralyzed veteran get up and around, keep a well groomed appearance, and engage in everyday activities. There are also some health care aspects of personal care services. For instance, while in bed paralyzed persons should be turned about every three hours to reduce the possibility of skin ulcers or bedsores.

Personal Hygiene: Since most paralyzed veterans have lost the function of their bowels and bladder, they must rely upon specific techniques to aid the excretory functions associated with these organs. For the veteran described above, bowel and bladder techniques require the assistance of an aide. Often the lower bowel has to be evacuated manually. The use of enemas or suppositories may suffice; however, an aide must perform the necessary tasks. The evacuation of urine may be promoted by external or indwelling catheterization. An indwelling catheter requires frequent changing by someone who is trained. Neglect of the services required with the indwelling catheter can result in death. The external catheter must be changed about every 24 hours to reduce the possibility of skin lesions and infection. Equipment associated with bladder evacuation must be kept clean, disinfected, and deodorized for the veteran's well being. Bathing would also be included in personal hygiene services for obvious reasons. Also a trained aide can recognize certain clinical signs of medical complications associated with paraplegia.

Travel: Spontaneity of travel is impossible for the paralyzed veteran. Every trip must be well planned or the replication of a previous trip. The outside world is not barrier free. The veteran in a wheelchair must be helped up and down curbs, up and down steps, and up and down steep inclines. Someone must help the paralyzed veteran carry groceries, parcels and luggage. If traveling any distance in a private vehicle, the veteran is subject to being isolated over night if a mechanical failure disables the vehicle. He cannot walk to a service station or phone booth. Changing tires is beyond the ability of most paralyzed veterans, they are at the mercy of passers-by if a companion is not available.

Household Care: If the severely disabled veteran wishes to maintain a home, there are many services pertaining to home care or housekeeping which he cannot do. Therefore, someone must assist him with cleaning, cooking and laundry.

SURVEY METHOD

In order to determine a reasonable estimate of the costs which would be incurred for the services described above, 56 randomly selected agencies in 12 states and the District of Columbia were contacted. Since most of the services listed would require individuals with some medical health care training or experience, all the agencies contacted offered personnel who were trained or licensed health care aides. Representatives from each agency contacted were asked which services their personnel were competent or able to perform within the following outline:

INQUIRY OUTLINE

1. Physical

- a. Range of Motion, or
- b. Passive Exercise

2. Personal Care

- a. grooming
- b. dressing
- c. clothes care
- d. transferring
- e. night rotation
- f. other (feeding, errands)

3. Personal Hygiene

- a. bowel care
- b. catheter care
- c. bathing
- d. equipment maintenance

4. Household Care

- a. cooking
- b. cleaning (dusting-vacuuming)
- c. laundry
- d. heavy cleaning (floors, windows etc.)

5. Travel

- a. shopping
- b. events
- c. out of town

Results:

Of the 56 agencies contacted, only the data from 43 agencies in 10 states and the District of Columbia could be used for computation. A list of all the agencies contacted is attached. (See attachment A.)

The results of the inquiries concerning services is reproduced in the table below:

SUMMARY TABLE OF INQUIRY RESULTS

	Physical Exercises	Personal Care	Personal Hygiene	Travel	Household Care
No. of Agencies which provide services	35	37	9	20	7
No. of Agencies which cannot provide services	3	0	0	3	0
No. of Agencies which provide limited services in the area specified	4	6	34	20	36

As indicated, in all service areas there were agencies which offered only limited services. In the area of physical exercises, four agencies felt that their aides could only perform the simplest passive exercises.

Under personal care, six agencies gave unclear answers about the size of the client being a determining factor for transferring, etc. Of course, if the aide refused to lift or transfer a heavy veteran, the aide could not perform total services adequately.

Under personal hygiene, thirty-three of the agencies indicated that their personnel were not allowed to change indwelling catheters. One agency indicated that their aides would not clean the equipment utilized in bowel and bladder care.

Twenty of the agencies contacted indicated some limitation as far as travel with the veteran was concerned. Most stated that their aides would not accompany the client unless he/she was visiting the doctor. Other agencies stated that their aides would not travel out of town. Still others indicated that travel was left up to the individual aide. All indicated that expenses incurred while traveling would be paid by the client.

Under household care, thirty-six of the agencies indicated that any cleaning would be light and limited to the client's immediate needs. Most male aides would not cook at all. Of the seven agencies indicating that housework was part of the aide's job, none distinguished between male and female aides.

It may be assumed that in all areas where only limited services are provided additional expenses would have to be paid by the paralyzed veteran for complete service.

The following section is a report of the rates which would have to be paid to the agencies for the services detailed above.

DETERMINATION OF RATES

Rates for services were based on a 24 hour live-in health care aide. A monthly cost was figured from daily rates by the following computational procedure:

$$\frac{DR \times 365}{12} = MC$$

Where DR is the daily rate in dollars and cents, 365 the number of days in a year, and 12 the number of months in a year, MC is the resulting monthly cost. If special weekly rates were available, the monthly cost was figured by the following computational procedure:

$$\frac{WR \times 52}{12} = MC$$

Where MR is the weekly rate, 52 the number of weeks in a year, and 12 the number of months in a year, MC is the resulting monthly cost. By this method, one day of the year is excluded.

RATES

For the 43 agencies used for computations, the calculated monthly rates ranged from \$760.42 to \$3193.73. The main reason for the variance appeared to be the geographic location of the agency and the qualifications of the personnel available for the service. Although an average rate of all agencies was \$1642.39, the distribution of rates indicated that average was biased by the extremely high rates charged by a few agencies. The table of frequencies and cumulative percentages presented below gives a visual description of the rate distribution.

RATE DISTRIBUTION

Rates In Dollars	Frequency	Cumulative Percentage
\$3100 - 3299	1	100
2900 - 3099	2	98
2700 - 2899	3	93
2500 - 2699	2	86
2300 - 2499	2	81
2100 - 2299	3	76
1900 - 2099		
1700 - 1899	3	69
1500 - 1699	4	62
1300 - 1499 Median \$1449.50	6	53
1100 - 1299	10	39
900 - 1099	6	16
700 - 899	1	2

As can be seen in the table above, a median rate of \$1449.50 illustrates a figure more accurately representing the rate range of all 43 agencies. 50 per cent of the agencies charged rates higher than \$1449.50 and 50 per cent charged rates lower. Thus, for the services described by the agencies represented in this survey, a median daily cost of about \$47.65 per day is expected.

The median figure of \$1449.50 may be somewhat high considering the rate schedules and the qualifications of the personnel available at the agencies contacted. Nearly 35 per cent of the agencies contacted did not offer a reduced rate for 24 hour service. Therefore, figuring 24 hour service at standard hourly rates may have inflated the rates.

Another estimate of the rate cost for 24 hour service was provided by Mr. John Hill, a Group Director for Homemakers, a division of Upjohn. Homemakers has 192 local agencies throughout the United States which provide health care personnel similar to the agencies used for this survey. Mr. Hill estimated the average rate charged by local Homemakers agencies for 24 hour service for the hypothetical case to be \$40.00 or \$1216.67 per month, which is similar to the mode rate illustrated in the distribution table above. Since local Homemaker offices charge rates according to the geographic location and competition, Mr. Hill's estimate may reflect a realistic figure.

Estimates can run considerably higher according to the personnel use. CHAMPUS pays \$81.40 per day for an actual case because CHAMPUS allows only the services of registered or licensed practical nurses. Another example of how specialized personnel can increase rates can be seen in Attachment B which shows the aid and attendance expenses being sought in settlement by an attorney for an individual claiming that his paralysis was caused by neglect while hospitalized in a civilian hospital.

An estimate of minimal requirements cost may be made from a program being conducted at the outpatient paralyzed veterans around the Palo Alto Veterans' Administration Hospital in California. On a fee basis, aides visit paralyzed veterans to perform necessary personal health care services. The actual cost to the VA is around \$16.35 per visit (4 hour minimum). The veteran described for this survey would probably require two visits at a cost of \$32.70 per day, or \$994.62 per month. Obviously, someone other than the aide would have to be available when the aide was not.

As shown in the table of services performed by the 43 agencies used in this survey, some essential services not provided would impose additional expenses upon the paralyzed veteran. The following section is concerned with these additional expenses.

HOME MAINTENANCE

Household maintenance might be defined as those activities or services necessary to maintain a person's home, adjacent grounds and household appliances, personal property, and other related items clean and in good repair.

Because of the inability of the severely disabled veteran to do many normal home maintenance activities such as lawn work, do-it-yourself repairs and adjustments, painting, house cleaning and other related work; it is necessary for the veteran to employ outside help or depend upon family members and friends to maintain his home. Either way, the disabled veteran will incur unusual expenses.

In order to determine an estimate of what expenses might be assumed by the paralyzed veteran who requires aid in the maintenance of his home, letters requesting hourly rates for house cleaning and/or lawn work were sent to 110 agencies advertising such services throughout the United States. After three weeks, only 7 agencies responded. Therefore, there is insufficient data available for a statistical estimate.

Information from the National Committee on Household Employment (see Attachment C) indicates that the average hourly wage of household cleaners in 13 major cities in the U.S. (two cities reporting wages lower than \$2.00 per hour were excluded) is \$2.61 per hour. Using \$2.61 per hour as an average wage for household work, the veteran, paying only the base rate for house cleaning four days a week, eight hours a day, would incur an expense of \$361.92 per month. As indicated in Attachment C, there is a strong possibility that other expenses would also be incurred such as when cooking is required. The estimated cost for someone who would prepare meals and clean five days a week is \$565.50 per month.

Information concerning the average wages actually asked by personnel who do lawn work and/or odd jobs is not available on a national level. Only the \$2.00 minimum wage required by the 1974 Amendments to the Fair Labor Standards Act of 1938 can be used for estimation. However, perceived variations for services which would be required with different properties and in different geographical areas make estimation impractical.

CONCLUSIONS

A conservative estimate of the average aid and attendance expense incurred by a paralyzed veteran similar to the one used for this survey would be \$1500.00 per month, allowing \$1100.00 for a live-in health care aide and \$400.00 per month for all additional expenses. Of course, expenses for aid and attendance may be lower or higher among paralyzed veterans according to their level of injury, their activity, and their properties.

The \$1500.00 aid and attendance requirement for the paralyzed veteran who wishes to remain independent of an institution takes on a new perspective when one realizes that the average daily cost of maintaining a paralyzed veteran in a Veterans Administration Spinal Cord Injury Center is \$89.25, which comes to \$2714.68 per month.

Also the cost of independence for the paralyzed veteran appears meager when one realizes that the Veterans' Administration expends about \$1089.83 per month to maintain a veteran in the closed sterile environment of a nursing home. The average of \$1089.83 per month includes the cost for all veterans in nursing homes, ranging from the catastrophically disabled such as our survey veterans, to individuals who are ambulatory and can provide some self care.

The purpose of this survey has been to determine a realistic cost of aid and attendance services necessary to allow the seriously disabled veteran to live outside of a hospital or institutional environment. The aid and attendance costs surveyed are separate and distinct from other compensating benefits. The accepted definition of compensation is that amount which provides financial recompense for disabilities incurred in service of the U.S. Military and the resulting loss of income earning potential. The purpose of aid and attendance benefits is to counterbalance those extraordinary expenses which are incurred as a direct result of the disability.

NOTE.-- The attachments referred to were not printed.

A SURVEY OF SPINAL CORD INJURED VETERANS: EMPLOYMENT, LIVING COSTS, AND HEALTH CARE

PARALYZED VETERANS OF AMERICA

DECEMBER, 1979

PROFILE OF SPINAL CORD INJURED VETERANS

Paralyzed Veterans of America recently completed a nationwide survey of spinal cord injured veterans. Information has been collected concerning health, education, and employment characteristics of the spinal cord injured veteran population. The survey was conducted during November and December, 1978.

Participants in the survey were selected randomly from PVA's membership. Approximately 10 percent of PVA's 10,000 members were asked to complete the survey. This number represents an estimated 4 percent of the total nationwide population of spinal cord injured veterans. From this initial group of 1,000 potential respondents, 465 SCI veterans completed the survey and returned it to PVA. The respondents represent a statistically large sample of the spinal cord injured veteran population. Since the information in this article is taken from a sample, the results should be viewed as estimates of total SCI veteran response. The size of the sample suggests that results are accurate within 4 percentage points. Thus, a percentage cited in this article (50%, for example) due to random error more properly should be interpreted as a range (46-54%). This 4 percentage margin is comparable to the 3 percentage range associated with the Gallup and New York Times/CBS opinion polls.

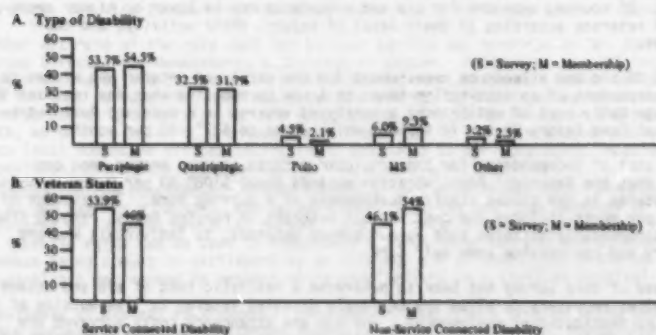
Reliability of Survey

Illustration 1 provides a description of the types of respondents in the survey. This information is compared with information obtained on the total membership, which historically has represented a respectable cross-section of the SCI veteran population throughout the country. This comparison indicates that the sample reflects the demographic characteristics of the spinal cord injured veteran population rather well.

From illustration 1.B, we see that the survey population is almost equally divided between service connected disabilities (53.9%) and non-service connected disabilities (46.1%). These figures are comparable to the entire membership, and thus to the spinal cord injured veteran population.

Likewise, the breakdown of respondents by type of disability is very close to the total membership. These comparisons indicate that our results do not represent some special sub-group within the organization or within the SCI veteran population. Rather, the results of the survey are applicable to the entire population.

Illustration 1
COMPARISON OF SURVEY RESULTS WITH MEMBERSHIP INFORMATION



EXECUTIVE SUMMARY

Paralyzed Veterans of America conducted a survey of spinal cord injured veterans to determine the employment status of this population, their income and expenses, and their health care needs.

Employment

Although over 90 percent of spinal cord injured veterans were employed prior to their injuries, only 15 percent of SCI veterans currently are employed. The major reasons for unemployment cited by those who are not working were medical problems (43.7%) and severity of disability (43.4%).

Those severely disabled veterans who do return to work usually have a college degree or better, and are likely to be employed in professional or administrative positions. The highest level of unemployment among SCI veterans occurs among those who have a high school degree or less (91.7% are unemployed).

Income and Expenses

The average annual income of service connected SCI veterans is \$25,817.41 compared to an average annual income of \$10,976.79 for non-service connected SCI veterans. Monthly income and expense figures for service connected and non-service connected veterans are compared. It is found that non-service connected SCI veterans spend considerably less on disability-related expenses than do their service connected counterparts, apparently because they are not able to afford the level of care that their disabilities require.

Health Care

Over 70 percent of SCI veterans use the services of the Veterans' Administration for their health care needs; an additional 8% use VA fee-basis care. This reliance upon the VA does not differ significantly between service connected and non-service connected SCI veterans, nor between paraplegics and quadriplegics.

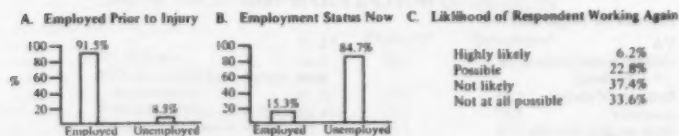
Employment

Illustration II presents information on the employment status of respondents prior to their injury as well as following their injury. These figures point to a rather dramatic shift in the employment status of respondents. While 91.5% of the respondents were employed prior to their injury, only 15.3% are employed now. Furthermore, of those presently working only 16.9% feel that the occupation they are employed in now is similar to the occupation they were employed in prior to their injury.

This high degree of unemployment is not caused solely by the severity of the disability of the respondent. Only about 52% of the respondents felt that their disability was so severe that they were dependent upon others for help. One possible reason for this high degree of unemployment is the lack of accessible public transportation to get to and from work. A resounding 71.8% of the respondents said that their town or region did not provide any type of accessible public transportation.

The outlook for future employment is also dismal. Table II.C. presents information on the respondents attitude toward future employment. Only 29% feel that it is possible or likely that they will be employed in the future. This is about 1/2 of the 71% who feel that employment is not likely or possible. Further incentive and accessibility programs are needed to resolve these problems.

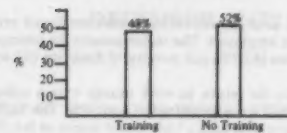
Illustration II
EMPLOYMENT STATUS

**Education**

The survey indicates that there is an almost equal split among respondents who have had additional training after their injury (48%) and those who have not had additional training (52%). The most often utilized source of additional training has been college (see Illustration III.B.). This is followed by graduate or professional school, trade school and high school. This training pattern indicates that a substantial majority of respondents have a high level of skill. In addition, 42% of the respondents felt that they would use additional training in the future. Skill or training do not provide a stumbling block on the road to re-employment for PVA members.

Illustration III EDUCATION

A. Additional Training Since Injury



B. Type of Additional Training

High school	5.1%
Trade school	18.0%
Attend/graduate college	39.0%
Attend/graduate grad/professional school	18.5%
Other	19.4%

C. Interest in Additional Training



Health Care

In recent years health care costs have skyrocketed. From Illustration IV.A, we see that a large majority of respondents turn to the VA for payment of hospitalization (71.1%). The remaining 29% is spread over the other available sources of payment. When respondents had to turn to a private doctor, other sources than the VA are the predominant source of payments. Personal income is the most often used source of payment (see Illustration IV.B). Since the use of private doctors is an important source of health care (about 68% of the respondents said they saw a private doctor), a large burden of health care cost is placed upon the recipient of that care. Considering that the average monthly cost of medical bills is \$64.25 (according to the survey), this is a substantial burden placed on the recipient of health care.

Illustration IV HEALTH CARE

A. Payment for Hospitalization

VA	71.1%
Military hospital/clinic	2.6%
VA - fee basis	8.0%
Medicare/Medicaid	6.1%
Insurance	4.7%
State medical benefits	.4%
Respondent pays all	1.3%
Respondent pays with some assistance	3.7%
Other	2.0%

B. Payment for Private Doctor

VA - fee basis	29.8%
Pay own bills	30.7%
Medicare/Medicaid	9.8%
Private insurance	7.3%
Other	3.2%
No answer	19.3%

This brief description of SCI veterans' needs point to a number of areas in which more detailed information is needed. The following sections of this report will investigate the effects of training on employment; the differences between service connected and non-service connected respondents' economic and health situations; and the rising cost of health care.

EMPLOYMENT AND THE SEVERELY DISABLED VETERAN

The severely disabled veteran should have both the right and the incentive to become an important part of the work force. Yet, the statistics found in the 1978 PVA survey show that the majority of respondents are not active participants in the work force. This article will outline this lack of participation and then explore the potential reason for the high unemployment rate. In looking at employment and the severely disabled veteran, this article will explore the relationship between education, placement services and qualifications, and the high unemployment rate.

I. Describing the Problem

Prior to their injury 91.5% of the respondents were employed. After the injury, only 15.3% of the respondents were employed. This is a rather significant transition — a transition which is not affected by the status of an individual respondent (Table I) nor the type of disability that an individual (Table II) has. Even when one considers the extent of disability, there is no clear difference between categories. When one looks at this breakdown (Table III), the respondents with less severe disabilities are not predominantly employed. The significance emerges as a result of comparing a 23% unemployment rate with a 2 percent employment rate. In looking at period of service and the employment rate, one finds that Vietnam era veterans have a slightly higher rate of employment than other respondents. Undoubtedly one of the reasons for this difference is the age of this sub-population. Table IV presents these results.

TABLE I: EMPLOYMENT STATUS & STATUS OF VETERAN

	Employed	Unemployed
Service connected	16.9	82.7
Non-service connected	12.7	87.3
	(n=462)	

TABLE II: EMPLOYMENT STATUS & TYPE OF DISABILITY

	Employed	Unemployed
Paraplegic	17.4	82.6
Quadriplegic	12.6	87.4
Other	12.5	87.5
	(n=462)	

TABLE III: EMPLOYMENT STATUS & EXTENT OF DISABILITY

	Employed	Unemployed
No assistance	23.1	76.9
With no architectural barriers and no assistance	24.8	75.2
Need help getting up in morning, etc.	18.9	78.4
Need help with most things	11.0	89.0
Need someone with me at all times	2.0	98.0

TABLE IV: EMPLOYMENT STATUS AND PERIOD OF SERVICE

	Employed	Unemployed
Prc WW II	3.4	96.6 (n=20)
WW II	13.7	86.3 (n=183)
WW II to Korea	5.6	94.4 (n=18)
Korea	14.3	85.7 (n=77)
Korea to Vietnam	14.0	86.0 (n=57)
Vietnam	25.5	74.5 (n=94)
Since Vietnam	0	100.0 (n=2)

There are many different reasons that severely disabled veterans are unemployed. Table V presents a list of potential reasons for the lack of employment. The 2 most often cited reasons for the respondents lack of a job are related to their medical problems.

TABLE V: REASONS FOR UNEMPLOYMENT

I am in school	4.7%	(n=22)
Too many medical problems	43.7%	(n=203)
Loss too much in disability benefits	21.3%	(n=99)
Disability is so severe that respondent is dependent on others	43.4%	(n=202)
Unable to find a job	10.5%	(n=49)
Turned down because of disability	8.4%	(n=39)
Employers ask uncomfortable questions	3.0%	(n=14)
Barriers are obstacles	17.2%	(n=80)
Uncomfortable out in public	3.4%	(n=17)
Getting ready takes too long	9.7%	(n=45)
Other sources of income are adequate	12.5%	(n=58)

Relevant Characteristics and Employment Status

Important variables to consider deal with the level of skill an individual has acquired. Vocational rehabilitation does have a slight effect on the potential for employment. Table VII presents the relationship between these 2 variables. Respondents who participate in vocational rehabilitation programs are more optimistic about obtaining employment in the future.

TABLE VI: FUTURE EMPLOYMENT & VOCATIONAL REHABILITATION

Future Employment		Vocational Rehab.	No Vocational Rehab.
Future Employment	Likely	13.0%	4.9%
	Possible	31.9%	21.2%
	Not likely	39.1%	35.9%
	Not possible	15.9%	37.9%

This attitude does seem warranted. The current employment rate for severely disabled veterans who have utilized vocational rehabilitation benefits is twice that of those veterans who have not utilized these benefits. But this distinction is not statistically significant. If one uses statistical significance as a criterion for accepting or rejecting the relationship, one must ignore this relationship. Vocational rehabilitation benefits do not significantly affect current employment. This lack of a relationship is captured in Table VII.

TABLE VII: VOCATIONAL REHABILITATION AND EMPLOYMENT STATUS

	Employed	Unemployed
Vocational rehab.	27.1%	72.9% (n=96)
No vocational rehab.	12.3%	87.5% (n=351)

(n=448)

Given this lack of a relationship, it is necessary to search for alternative routes to employment for the severely disabled veteran. The type of additional training after an injury has no significant effect on the type of occupation an individual respondent currently holds. Likewise, the highest level of schooling has no significant effect on current occupation type. The type of pre-injury employment seems to be the most significant indicator of an individual's current occupation. But the number of respondents is so small (n=74) and the number of empty cells in the matrix so large, that the results are not very conclusive. The most often cited occupation is a professional. (46.9% of the respondents holding a job said this was their current occupation.) This is followed by administrative positions and craft positions. Table VIII presents this description of the small group of respondents who are currently employed.

When one looks simply at employment status, a slightly different relationship emerges. The type of additional training does affect employment status, as does the level of schooling.

TABLE VIII: CURRENT OCCUPATION OF RESPONDENTS

Professional	46.9%
Administrative	18.8%
Cherical	4.7%
Sales	7.8%
Farmer	1.6%
Transportation & Communication	1.6%
Craftman	12.5%
Service	4.7%

(n=64)

The type of pre-injury occupation, on the other hand, has no effect on current employment status. This suggests that additional training through conventional sources may help an individual obtain a job, but it has no direct effect on the type of occupation he will acquire. A person's previous work experience is much more likely to determine current occupation. These findings suggest that a college education is a much more important training tool than vocational rehabilitation in securing employment for the disabled veteran. Table IX presents these results on additional training.

TABLE IX.A: ADDITIONAL TRAINING & EMPLOYMENT STATUS

Level of Education		
	Employed	Unemployed
High school	8.3	91.7
Trade school	16.7	83.3
Attend college	18.8	81.3
Finish college	25.9	74.1
Attend graduate/professional school	31.6	78.4
Finish graduate school	62.5	37.5
Other	20.0	80.0

(n=460)

TABLE IX.B: EMPLOYMENT STATUS & HIGHEST LEVEL OF SCHOOLING PRIOR TO INJURY

	Employed	Unemployed
Junior high school	6.6	93.4
High school	13.2	86.3
Trade school	4.0	96.0
Some college	17.5	82.5
College degree	37.9	62.1
Some graduate/professional school	40.0	60.0
Graduate/professional degree	33.3	66.7
Other	8.3	91.7

(n=460)

These results are somewhat surprising when one considers the relatively high level of schooling the group of respondents utilized. Over 55% have utilized additional training benefits, yet there is still a low level of employment for the group. (See "Profile of Spinal Cord Injured Veterans" for the level of utilization of education benefits.) There must be some type of disincentives which do not promote employment. There are 2 reasons which seem to have an effect on employment. The threat of losing disability benefits and other sources of income separate service connected and non-service connected respondents. Non-service connected respondents are more likely to feel that they will lose disability benefits, while service connected respondents are much more likely to feel that other available sources of income are adequate. This, of course, corresponds to the fact that the major sources of income for non-service connected veterans are Social Security Disability Insurance and VA pension, which are no longer paid when the individual demonstrates an ability to work. Disability compensation to service connected veterans is paid regardless of whether or not the veteran is working. Table X presents these cross-tabulations.

TABLE X: REASONS FOR UNEMPLOYMENT

	Loss disability	Do not lose disability
Service connected	16.5%	83.5%
Non-service connected	35.1%	64.9%

(n=391)

	Other sources adequate	Other sources inadequate
Service connected	21.7%	78.3%
Non-service connected	7.0%	93.0%

In addition, service connected respondents are more likely to have held a full-time job since their injury than non-service connected respondents. These results are presented in the final table, Table XI.

TABLE XI: FULL-TIME JOB SINCE INJURY

	Full-time job	No full-time job
Service connected	36.7%	63.3%
Non-service connected	13.5%	86.5%

INCOME: COST OF LIVING AND THE SEVERELY DISABLED VETERAN

Introduction

It is common knowledge that the cost of living has sky-rocketed in this country. A number of sectors of the economy have fueled this inflationary spiral. Health care costs and transportation costs are two of the most significant sectors contributing to this increase. Inflationary costs affect different sectors of the nation in differing degrees. Especially hard hit by inflation are those segments of the population living on fixed incomes. An investigation of income and cost figures is necessary in fully understanding the everyday experience of the severely disabled veteran, a potential member of this fixed income group. The role of inflation in the day-to-day living experience of the severely disabled veteran can be seen in numerous comments that were returned with the survey. One comment sums up the position of the severely disabled veteran in a succinct manner: "My income is so limited any added expense creates a hard-ship." The most passionate response was provided by one respondent in his attempt to provide information on expenses. He replied:

I can not complete this monthly budget, it depresses me to have to see it in black and white. All I can say is I am grateful each month I find I can cover the expenses that come up. We have not had a vacation expense since my husband's disability, and probably never will...with recent increases we make ends meet, but have many fears and we are not comfortable at all.

The extent of the hardship is easily seen when one considers that the severely disabled is highly dependent on these two sectors - health and transportation - which have shown tremendous inflation. There is heavy dependence on a wide range of health care systems. Likewise, due to the lack of accessible public transportation, the severely disabled veteran has to absorb a large amount of the high costs associated with transportation. The inflationary expenses associated with health care are suggested by one respondent who suggested: "If an extreme medical expense hit my family, God knows how I could handle it." Another commented: "We are able to manage okay except when I am in the hospital...then we are in a bind, as we are right now." Rising transportation costs are reflected in the comment "Yes at the present time I do have a very difficult time meeting expenses and can hardly afford gas to any place."

This article will investigate income and cost by looking at a number of categories of these figures. The first category under investigation will be income. Information will be provided on the source and amount of income obtained from the different available sources. Expense information will be broken down into four categories: medical expenses, disability related expenses, monthly expenses and miscellaneous expenses. Medical expenses cover those costs directly associated with health care: medical bills, supplies, prosthetic equipment and medical aid. Disability related expenses cover those costs which a severely disabled veteran incurs as a result of a disability. Things like cost of household help, lawn care and other "extraordinary" expenses are included in this category, as well as those costs incurred as a result of relying on other individuals to maintain one's health and residence. These costs should be considered as necessary in the day-to-day activity of the severely disabled veteran and should not be viewed as exorbitant. The miscellaneous expense category includes cost information for entertainment, gifts and other expenses. Finally, monthly expenses covers those costs incurred by all individuals in their day-to-day living.

While the information contained in this article can be viewed as a "balance sheet" for incomes and costs of severely disabled veterans, a more appropriate way to view this information is as indicators of standard of living. The amount of missing information discredits this analysis as an accurate accounting of the income and cost information for these veterans. But the information does provide an indication of how much income is coming in, and what areas it is spent on. Cost figures indicate what is important and perhaps necessary in the day-to-day existence of an individual.

Unlike the previous section, results of this analysis can not be presented in tabular form. When we are dealing with amounts of money, there is a wide range of answers available to the respondent, rather than a small number of predetermined categories. There are a number of ways to resolve this problem. One is to collapse ranges of dollar amounts into ad hoc categories. While this would provide a tabular format for the presentation of information it could bias the results of the analysis. A strong criticism of this approach would be that there is no viable justification for the dividing points for the categories. If one would change the dividing points, we might end up with very different results.

A more reasonable alternative is to provide summary measures of dollar amounts. These measures can be compared for sub-populations. This type of comparison is much more rigorous than the tabular format, and less likely a target of criticism. The type of summary measure included in this analysis will be the mean. The mean is the average income. A summary measure reflecting the distribution around this average will also be provided. This is necessary since it will indicate if the average is influenced by a few extreme numbers. For example, one may have two groups with an average of fifty. One group composed of three individuals with income of \$48, \$50 and \$52; the second group may be composed of three individuals with income of \$1, \$99, and \$50. Failure to provide measures of the distribution will eliminate this important distinction from the analysis.

I. MONTHLY INCOME FIGURES

A. Disability Compensation

Disability compensation is an important source of income for the service connected veteran. The average monthly income for the service connected respondent from disability compensation is \$1,752.22. Ninety percent of the two hundred thirteen service connected respondents fell within the range of \$2,130 - 1,374.

B. Pension

An important source of income for the non-service connected veteran is the VA pension. Sixty-two percent of the non-service connected respondents (n=134) provide information on the amount of their VA pension. As a group the non-service connected respondents receive about \$248.28 per month in pension payments. Ninety percent of these responses fell in the range between \$151.13 - 345.43.

C. SSDI

Both the non-service connected and service connected sub-populations rely on SSDI payments as an income source. Sixty-three percent of the service connected respondents provided information on this source of income, while seventy percent of the non-service connected respondents provided this information. The average income for the service connected respondents is \$321.93, while the average income for the non-service connected respondents is \$153 - 419, while ninety percent of the non-service connected fell in the \$210 - 433 range.

D. Social Security Retirement Income

A very small percentage of respondents provided information on the amount of Social Security retirement income they receive. Only five point two percent of the sample responded to this question. Fifteen out of two hundred fifty-one service connected respondents provided information. The average income for these respondents is \$231.60. The average income of the nine non-service connected respondents is \$282.44. The number of respondents is so low that it does not warrant dispersion statistics.

E. SSI

SSI is a potential source of income for non-service connected veterans. In the PVA sample only eight out of two hundred fourteen provided information on this source of income. The average income is \$210.22.

F. Workmen's Compensation

Only seven respondents provided information on workmen's compensation. The service connected respondent's average income from this source was \$18.00; while non-service connected respondents' average income was \$402.00. These statistics are very misleading, however. Ninety percent of service connected respondents fall between \$55.00 and \$749.00. The sample is much too small to view this as a legitimate and significant difference.

G. Insurance Payments

Only three point five percent of the respondents rely on insurance payments as a source of income. This provides us with a sub-population of seventeen respondents to make comparisons. The eight non-service connected respondents received an average of \$401.00 in insurance pay, while the nine service connected respondents received an average payment of \$182.11.

H. GI Bill Benefits

Neither NSC nor SC respondents actively use GI bill benefits. Only two point six percent of the total sample use the bill as a source of income. The service connected respondents have an average income of \$207.43, while the non-service connected respondents obtain \$233.00.

I. Spouse's Unearned Income

Only ten point four percent of the respondents rely upon a spouse's unearned income as another source of income. The forty-nine respondents providing this information were composed of twenty service connected respondents with an average income of \$267.45 and twenty-nine non-service connected respondents with an average income of \$287.17. Ninety percent of the NSC respondents fall between \$0 - \$74; while ninety percent of the SC respondents fall between \$0 - 620.

J. Veteran's Earned Income

Only thirteen percent of the respondents have an earned income. Sixty percent of these are service connected while the remaining forty percent are non-service connected. The average income for service connected respondents is \$1,289.76, while the average figure for the non-service connected is \$2,235.33. An equally interesting characteristic is that ninety percent of the service connected fall between zero and \$3,038.00; while ninety percent of the non-service connected respondents fall between zero and \$4,749.00.

K. Spouse's Earned Income

Thirteen percent of the respondents received income from their spouse's working. Seventy percent of these respondents were non-service connected. While changing social patterns obscure the importance of these findings somewhat, the large preponderance of NSC wives in this category suggest that NSC respondents need other sources of income to cover costs. The average spouse's income of SC respondents is \$662.66 as compared to \$1,103.59 for non-service connected respondents. Likewise the range between these two sub-populations is substantial. Service connected income ranges between \$100.00 and \$796.00, while non-service connected income ranges between zero and \$3,159.00.

L. Other Income

Twenty percent of the respondents rely upon other income sources. Service connected respondents have an average income of \$301.88 while NSC respondents average \$570.59. The service connected sub-population is a tightly bunched group with ninety percent falling between \$50.00 and \$546.00; while the NSC is spread out between zero and \$2,000.00.

A summary table of this monthly income data is provided in Table I. From this table one can see that excluding those categories where each of the sub-group does not meet the eligibility requirements, there is no significant difference in the source of available income. The major difference between the two groups is in the dollar amount which is provided each eligible group separately. Service connected respondents receive an average \$1,752.22 in disability compensation, as compared to the \$248.00 in pension benefits and the \$210.00 in SSI payments which have been used almost exclusively by non-service connected respondents.

TABLE I: SUMMARY TABLE SOURCE OF INCOME AND AVERAGE INCOME

Income Source	Service Connected	Non-service Connected
Disability Compensation	\$1,752.22	
Pension		\$ 248.28
SSDI†	268.08	321.93
Social Security Retirement Income*†	231.60	282.44
SSI*		210.12
Workmen's Compensation*†	18.00	402.00
Insurance Payments*†	182.11	401.25
GI Bill Benefits*†	207.43	233.00
Spouse's Unearned Income†	267.45	287.17
Veteran's Earned Income†	1,289.76	2,235.33
Other Income†	301.88	570.59
Spouse's Earned Income	662.66	1,103.59

† No statistically significant difference.

* Less than 10% of sub-population provided information.

This monthly breakdown of income does not accurately depict the large discrepancy between non-service connected respondents and service connected respondents. The inequality in the level of income between these two groups is captured in the yearly income figures reported by the two groups. The average yearly

income for service connected respondents is \$25,817.41. This compares with an average income figure of \$10,976.79 for non-service connected respondents. The average yearly income figure for SC respondents is more than twice the figure for non-service connected respondents.

This is a rather significant difference. As will be found in the analysis on expenses, this difference between the two sub-populations is reflected in life style. The non-service connected respondent compensates for this lower income level by attempting to reduce costs by utilizing health care facilities that are less costly (either by cutting down his usage or perhaps turning to less costly inferior care) and maintaining a lower life style than the service connected respondent.

II MONTHLY EXPENSES

House Payments

Seventy-six percent of the respondents must incur the monthly cost of house payments. The average cost of these payments is \$364.00 per month. Service connected respondents pay an average cost of \$357.00 while non-service connected respondents pay \$237.00. Ninety percent of the service connected fall in the category between zero and \$800.00; while ninety percent of NSC respondents fall in the category between zero and \$1,000.00.

Food

About ninety percent of the respondents said they must pay for their food. The service connected respondents pay an average food bill of \$270.89, while the non-service connected pay \$186.57. The dispersion for these two sub-groups is slightly different - ninety percent of SC respondents have costs which range from \$136.00 to \$400.00, as compared to a range of \$80.00 to \$294.00 for the non-service connected respondents. There is a significant difference between the service connected and non-service connected respondents.

Clothing

Like food, clothing shows a significant difference between the service connected and non-service connected respondents. The average monthly cost of clothing for the service connected respondent is \$91.11, as compared to \$50.52 for the non-service connected. The dispersion measure shows a much wider dispersion for the service connected as well. This suggests SC respondents are willing to spend more on clothing. Ninety percent of the SC respondents spend between zero and \$193.00; while NSC respondents spend between zero and \$134.00.

Utilities

Service connected respondents must incur an average monthly utility cost of \$136.65. Non-service connected respondents spend on the average \$91.39 per month on the utilities. Eighty-three percent of the service connected respondents incur this cost as compared to seventy-two percent of the non-service connected. The range of dispersion for SC respondents is between \$63.00 and \$200.00; between \$38.00 and \$144.00 for non-service connected.

Car/Van Payments

About fifty-one percent of the respondents in the sample must incur the cost of car/van payments. Sixty-four percent of these respondents have service connected disabilities. Fifty-six of the SC respondents pay car/van payments; while only thirty-eight percent of the NSC sub-population incur this. The average payment for the SC respondent is \$197.35 as compared to \$110.56 for the NSC respondents. Likewise the range of dispersion for SC respondents is between \$95.00 and \$300.00; \$53.00 and \$167.00.

Gasoline Payments

About eighty percent of all respondents must pay for gasoline. This figure suggests that the previous category of car/van payments underestimates the cost of transportation for the respondents. The eighty percent figure suggests that a large minority of respondents either pay cash or have already paid up the cost of their car/van.

Service connected respondents pay an average of \$77.72 for gas; non-service connected respondents pay an average of \$44.74. Dispersions for SC respondents is between \$26.00 and \$128.00, as compared to NSC respondents falling within the range of \$14.00 and \$74.00.

Property Taxes

There is no statistically significant difference between SC and NSC respondents on payment of property taxes. Fifty-two percent of the respondents had to pay property taxes. Fifty percent of SC respondents must incur this cost while forty-five percent of NSC respondents provided this information. The average property tax payment of the NSC respondent is \$65.13. Without controls for tax structure in each locality these figures do not provide a strong comparative base.

Income Tax

Only twenty-five percent of the respondents pay income tax. There is no substantial difference between the SC/NSC sub-populations. The SC respondents pay an average tax of \$175.31 as compared to \$174.17 for the NSC respondent. Both have ninety percent of their respondents falling in the range of zero and \$400.00. This finding suggests (and is supported in the earlier section on earned income) that each sub-population earns about the same monthly income.

Insurance Premiums

Seventy-one percent of all respondents pay monthly insurance premiums: Seventy-four percent of the SC population and sixty percent of the NSC population. The SC population pays a monthly fee of \$62.99 as compared to the \$48.55 of the NSC population. The SC population has a dispersion range of \$30.00 to \$94.00 as compared to the \$17.00 to \$79.00 range of the NSC population.

This monthly expense data is summarized in Table II. Table II presents an interesting picture for comparison. In every case NSC respondents incur lower costs than SC respondents. Undoubtedly, this is a result of the lower standard of living forced upon the NSC sub-population; their lower income status is being compensated by reduced monthly needs. One NSC respondent commented "we live on a very tight budget. There is no in between. We must be thankful to our family and friends for aid in the form of clothing, friendship and whatever else they can offer." The reduction in daily expenses of the NSC respondents is suggested by this comment: "I am broke all the time - I do not go out or have recreation - I am forced to eat very little to be able to survive." Many NSC respondents commented on the life style forced upon them: "My life style is very unsatisfactory," "I live in a poor rent area," "I don't feel we have a life style, but merely an existence." These type of comments underscore the lower standard of living NSC respondents put up with.

TABLE II: SUMMARY TABLE OF AVERAGE COST

Monthly Expenses	Service Connected	Non-service Connected
House Payments	\$357.50	\$237.42 (n=335)
Food Payments	270.89	186.61 (n=400)
Clothing	91.11	50.51 (n=384)
Utilities	136.65	91.39 (n=366)
Car/Van Payments	197.35	110.56 (n=223)
Gasoline Payments	77.72	44.74 (n=348)
Property Taxes*	89.63	65.13 (n=224)
Income Tax	175.31	174.17 (n=109)
Insurance Premiums	62.99	48.55 (n=314)

*No statistically significant difference.

III. MEDICAL EXPENSES

In describing monthly medical expenses two different analyses have been done. The first considered the status of an individual and monthly medical expenses. The second considered the type of disability and medical expenses. There was no statistically significant difference in any of the breakdowns in this category of cost. This is a somewhat surprising result. The status of an individual or the type of disability do not affect his medical expenses. One of the reasons for this result is the low response rate. Another reason for this result could be the extent to which a given individual depends upon the VA for his medical care, medical supplies, and prosthetic equipment. Since the VA does not charge the veteran for care or equipment, the veteran would not incur any expenses for VA-provided services. As can be seen from the analysis presented below, there appears to be differences in cost figures for these groups. But since the number of individuals in each category is small, the differences do not meet the stringent requirements associated with statistical significance.

Medical Bills

Sixty percent of the respondents said they had to incur the cost of monthly medical bills. Sixty-seven percent of the service connected respondents had to incur the cost of these bills, while fifty-two percent of the NSC respondents provided cost information. Service connected respondents pay average monthly bills of \$70.10, as compared to the \$55.13 average cost of non-service connected respondents.

When one breaks these cost figures down by the type of disability, the average monthly medical bill for paraplegics is \$67.83, for quadriplegics \$47.81 and for the residual category is \$81.24.

Medical Supplies

Forty percent of the respondents must incur the expense of medical supplies. Thirty-six percent of service connected respondents incurred these costs. Thirty-seven percent of non-service connected respondents paid these costs. The average cost for service connected respondents was \$32.30, the non-service connected respondents paid \$23.92. Ninety percent of non-service connected respondents fall between zero and \$49.00 while service connected respondents costs ranged between zero and \$68.00.

Thirty-eight percent of the paraplegics paid for medical supplies, while thirty-four percent of the quadriplegics incur their cost, and forty-two percent of the residual category must absorb these costs. The average cost of medical supplies for paraplegics is \$26.12, for quadriplegics \$30.92 and for the residual category, \$33.89.

Prosthetic Equipment

Twenty percent of the total sample had to incur the cost of prosthetic equipment. Sixteen percent of the service connected respondents, and non-service connected respondents provide information on these costs. The service connected respondents average cost is \$71.58 as compared to \$68.11 for non-service connected. Ninety percent of the service connected pay costs that range from zero to \$176.00, as compared to a range of zero to \$177.00 for non-service connected.

When we breakdown prosthetic equipment cost by type of disability, one finds that seventeen percent of the paraplegic respondents paid for this equipment, seventeen percent of the quadriplegic respondents paid for the equipment, while only twelve percent of the residual category paid for this equipment.

The average amount of money spent on this equipment is \$54.51 for paraplegics, \$83.77 for quadriplegics, and \$68.76 for the residual category.

Attendant Care

The final category covered under medical expenses is attendant care. When considering service connected or non-service connected respondents, there is a large difference in cost. Service connected respondents pay an average cost of \$273.53 as compared to the average cost of \$187.16 for non-service connected respondents. This distinction points to the large difference in the degree of usage of attendant care. The service connected respondents and non-service connected respondent show the same type of medical needs, yet there is a difference in costs of medical expenses. One of the reasons for this difference is the under utilization of health care facilities. Service connected respondents with their higher incomes are more apt to utilize attendant services than the non-service connected.

When one breaks down this expense by the type of disability, a large difference occurs between paraplegic and quadriplegic respondents. Paraplegic respondents pay an average cost of \$150.74 as compared to \$334.73 for quadriplegic respondents.

Twenty-six percent of the service connected respondents use attendant care, as compared to sixteen percent of the non-service connected respondents. Fourteen percent of the paraplegic respondents utilize attendant care as compared to twenty-nine percent of the quadriplegic respondents.

The characteristics found in this last category are also reflected in the overall medical expenses paid by each of these sub-groups. In order to get an estimate of average total medical expense, each of the above categories were summed. That is, total medical expense is equal to the cost of medical bills, medical supplies, prosthetic equipment and medical aid. In almost all cases an individual does not have to incur a cost in each category. As a result these average costs are somewhat blind. The only respondents left out of this summary analysis are those who incur no costs.

Seventy-two percent of the respondents provide some cost information and as a result were included in the estimate of this summary measure. Seventy-seven of the service connected respondents were included in the analysis. Sixty-five percent of the non-service connected respondents were included. A large majority of respondents must incur some medical expenses. The average expense for service connected respondents is \$175.41, for non-service connected respondents this expense is \$114.73. These averages suggest that SC respondents are willing to incur large costs to maintain their health as compared to NSC respondents.

A comparison based on type of disability summarizes the individual item differences presented earlier. Paraplegics pay an average medical expense of \$114.26. This is compared with the higher expense of \$206.85 incurred by quadriplegics. The bulk of this difference is undoubtedly a result of quadriplegics increased medical aid costs.

TABLE III: SUMMARY TABLE OF MEDICAL EXPENSES

	Service Connected	Non-service Connected		
Monthly Medical Bills	70.10	55.13		
Medical Supplies	32.30	23.92		
Prosthetic Equipment	71.58	58.11		
Medical Aid	273.53	187.16		
			Para- plegic	Quadri- plegic
Monthly Medical Bills			67.83	47.81
Medical Supplies			26.12	30.92
Prosthetic Equipment			54.51	83.77
Medical Aid			150.74	334.73
			(n=249)	(n=151)
				Other
				81.24
				33.89
				68.75
				189.23
				(n=64)

TOTAL MEDICAL EXPENSES

Service Connected	Non-Service Connected	Para- plegic	Quadri- plegic	Other
175.41	114.73	114.26	206.85	189.52

Disability Related Expenses

1. Household help

There is a big difference between the amount of money spent on household help by service connected as compared to non-service connected respondents. Service connected respondents spent on the average \$114.44 per month on household help as compared with the \$85.90 per month spent by the non-service connected respondents. This difference is primarily a result of available funds, there is no clinical difference between these subgroups, so there is equal need for household help. Yet, service connected respondents spend considerably more for their help.

When we break down the average monthly amount spent on household help by type of disability, there is no significant difference. Paraplegics spend an average of \$107.66, quadriplegics spend \$95.55, and the residual group spends \$119.50.

2. Lawn care

Lawn care is another potential category of costs associated with a disability. As with household help, there is a significant difference between service connected and non-service connected respondents. Service connected respondents spend an average of \$94.42 as compared to \$55.23 for the non-service connected respondents. There is no significant difference between respondents when we make a comparison based on the type of disability. Paraplegics have an average cost of \$79.65, quadriplegics spend an average cost of \$83.30, the residual groups spends the most with an average fee of \$88.77.

3. Extraordinary expenses

There is no significant difference between sub-populations in terms of extraordinary expenses. Service connected respondents spend \$134.47 as compared to \$125.33 for non-service connected respondents. About thirty-seven percent of the service connected respondents said they must incur these costs as compared to about twenty-five percent of the non-service connected respondents. This lack of variance also is found when one breaks down the cost of extraordinary expenses by type of disability. Paraplegics have an average cost of \$136.02 as compared to \$127.65 for quadriplegics and \$121.53 for the residual category.

Total Disability Expenses

The significant difference between the service connected and non-service connected respondents is best seen in a composite indicator of total monthly disability related expenses. This indicator is a summation of all disability related costs: household help; lawn care and extraordinary expenses. Respondents who said they incurred no costs in any of these categories were ignored in the analysis. This leaves a sample of three hundred twenty-four respondents, about seventy percent of the survey respondents. Eighty percent of the service connected respondents are part of the analysis, and about fifty-six percent of the non-service connected respondents.

Service connected respondents incur an average cost of \$209.87 as compared to the \$131.17 for the non-service connected respondents. This significant difference underscores the significant difference in the standard of living between these two groups. Service connected respondents with their larger income are able to incur a higher level of cost for those things associated with their disabilities. This does not suggest that disability related needs are met for any sub-population, but rather that there is inequalities in the ability to absorb the burden of these necessary living expenses. Table IV presents these average costs.

TABLE IV: AVERAGE DISABILITY RELATED EXPENSES

	Service Connected	Non-service Connected	
Household Help	\$114.44	\$ 85.90	
Lawn Care	94.42	55.23	
Extraordinary Expenses	134.47	125.33	
	Para- plegic	Quadri- plegic	Other
Household Help	\$107.67	\$ 95.55	\$119.50
Lawn Care	79.66	83.30	88.77
Extraordinary Expenses	136.02	127.65	121.53
	Service Connected	Non-service Connected	
Total Disability Expense	\$209.87	\$131.17	

Other Expenses

This pattern of non-service connected respondents having a much smaller disposal income than the service connected respondents also occurs when we look at miscellaneous expenses:

1. Entertainment expenses

The average amount of money spent on entertainment by service connected respondents is \$108.25 as compared to \$43.53 for non-service connected respondents. About sixty-one percent of the service connected respondents said they spent money on entertainment. This compares with the forty-one percent of the non-service connected respondents who incur this cost. This suggests that not only are service connected respondents willing to spend more on entertainment, but also that these respondents are more willing to spend any money on entertainment. There is no significant difference when one breaks down these expenses in terms of type of disability.

2. Gifts and miscellaneous expenses

Service connected respondents spend on the average \$75.85 for gifts and other miscellaneous expenses. This figure is much greater than the average \$49.18 that non-service connected respondents spend on gifts. Forty-six percent of the service connected respondents said they spend this money, which is equal to the thirty-eight percent of the non-service connected respondents.

3. Other expenses

Only twenty percent of the respondents said they paid other expenses. Twenty-three percent of the service connected respondents said they paid these costs, only thirteen percent of the non-service connected respondents paid these costs. Service connected respondents paid an average cost of \$190.05, this is over twice the figure for the non-service connected of \$88.32. But these figures are somewhat misleading. Since this is a residual category, there is no explicit definition for these expenses. As a result the figures may represent a comparison of high cost and low cost items. Also, since the number of respondents is so small, the results do not meet the more stringent requirements associated with tests for statistical significance. Table V summarized the results of these final expense items.

TABLE V: AVERAGE MISCELLANEOUS EXPENSES

	Service Connected	Non-service Connected
Entertainment	\$108.25	\$ 43.53
Gifts/Misc. Expenses	75.85	49.18
Other*	190.05	88.32

	Para- plegic	Quadri- plegic	Other
Entertainment*	\$181.53	\$ 87.53	\$ 71.47
Gifts/Misc. Expenses	75.48	61.27	48.55
Other*	181.53	122.79	137.78

*No statistical significance

Summary

The most obvious result of this analysis is the tremendous difference in income and cost figures between the non-service connected respondent and the service connected respondents. The non-service connected respondents have a considerably lower yearly income and as a result compensate by maintaining a life style which is considerably less costly than the service connected respondents. This life style includes a working wife, which in the severely dependent respondents, can put a tremendous strain on the familial situation.

This comparison does not suggest that service connected respondents "have it made," but, rather that the benefit system is giving them a better chance to meet the day to day needs of the severely disabled veteran.

The study of health care use and source of payment is concerned with attempting to discern what are the major sources of health care and payment for selected sub-groups of veterans. The analysis will concentrate on the dichotomy between service connected and non-service connected veterans. This dichotomy was chosen since it plays such an important role in the decision of eligibility for many available health services. It is important to note that most of the information contained in this article focuses on the target of health care systems. It provides a view of what services each sub-population uses. It does not provide information on the caseload mix of each of these health systems.*

In looking at available health care facilities this analysis will consider two distinct aspects of the health care delivery system: acute care and continuing care. Acute care information will provide information on initial hospitalization, rehabilitation, and the usage of initial hospitals and its relation to rehabilitation services. Continuing care will investigate inpatient and outpatient histories as well as information on other sources of medical care.

As can be seen by the topics under each of these listings, the initial breakdown into these two topics is somewhat artificial. Inpatient histories can be considered part of the caseload of acute care facilities. The information on reasons for inpatient hospitalization, however, suggest that the most predominant reasons for inpatient hospitalization are not to meet acute problems. As a result, in the presentation of this survey information, it has been assumed that initial hospitalization is the primary element of acute care demands on health services available to the veteran. This is a guarded assumption. If anything it probably means that information on acute care facilities is somewhat underestimated when describing caseload mix.

I. ACUTE CARE

A. Initial hospitalization

When a severely disabled veteran seeks initial hospital care there are a number of available sources of hospitalization. The availability of the source is dependent upon eligibility requirements and the situation surrounding the injury. Looking at the total sample of respondents we can discern that the most often used source of initial hospitalization is the civilian hospital followed by the military hospital and the VA hospital. Table I.A. presents these results.

Civilian hospitals are the largest provider of initial hospitalization for severely injured veterans. Upon breaking this distribution down by the status of eligibility (i.e., was the injury service connected or non-service connected), the reason for civilian hospitals as a model category becomes obvious. Table I.A.1. presents these results. The Table shows a significant difference ($p < .0001$) between these two groups.

TABLE I.A.: INITIAL HOSPITALIZATION

Source of Initial Hospitalization	Frequency (%)
Civilian	43.9
Military	39.4
VA	15.6
Other	1.1

(n=462)

*In a few cases an estimate of this mix is provided. These figures, however, can only speak for a small sub-population of the entire load on these large health systems.

TABLE I.A.1.: INITIAL HOSPITALIZATION AND STATUS

	Military	VA	Civilian	Other	
Service Connected	69.8	10.1	19.8	0.4	
Non-Service Connected	4.2	22.1	71.8	1.9	(n=461)

This data presents a picture of two distinct entry processes into the health system for these two sub-groups. A majority of service connected veterans enter through military hospitals, while a large majority of non-service connected veterans initially rely on civilian hospitals. This distinction is more poignantly seen in looking at the make-up of the mix of patients who utilized each source of hospitalization. Table I.A.2. presents these results. (N.B.: These figures are used to strengthen the previous argument. They should not be viewed as an accurate measure of the caseload mix for each health system.)

TABLE I.A.2.: CASELOAD MIX OF INITIAL HOSPITAL

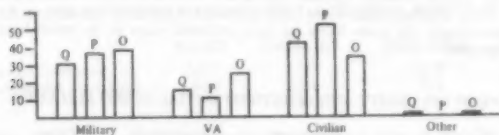
Type of Hospital	Veteran Status		
	Service Connected	Non-service Connected	
Military	95.1	4.9	(n=182)
VA Hospital	34.7	65.3	(n=72)
Civilian Hospital	24.3	75.7	(n=202)
Other	20.0	80.0	(n=461)

From Table I.A.2. we can see that 95% of all respondents who utilized military hospitals were service connected; while about 76% of those utilizing civilian hospitals were non-service connected. What is extremely interesting about this table is that VA hospital utilization as an initial source of health care primarily occurs as a result of non-service connected injuries.

Another potential source of the overall distinction in initial hospital usage is the type of disability the individual has. (This is a strict post-hoc argument: The type of disability is obviously diagnosed after entry into the health care delivery system.) From Table I.A.3 one can see that there is a difference in initial hospital usage based on disability. The residual category comprised of polio, multiple sclerosis, and other disabilities show a different distribution of usage than does quadriplegic and paraplegic respondents. In the case of the residual category there is no clearly predominant source of initial care. While in the plegic responses civilian hospitals and military hospitals are the initial sources of hospitalization most often utilized, in the case of the residual category, a substantial number of respondents also utilize the VA system for initial care.

TABLE I.A.3.: INITIAL HOSPITALIZATION AND DISABILITY

	Military	VA	Civilian	Other	
Type of Disability	Quadruplegic	40.7	16.1	41.5	1.6
Paraplegic	37.7	10.6	51.7	- 0 -	
Other	38.7	25.8	33.9	1.6	(n=461)



[Q=Quadruplegic; P=Paraplegic; O=Other]

Combining these two previous categories in the investigation of initial hospitalization, Table I.A.3.a. presents information for disability and status* with initial hospitalization.

The importance of the mix of these two variables and the patterns established in the two previous tables is manifested in this summary table. The "Other" category shows distribution across all sources of initial hospitalization. The service connected respondent, whether a quadriplegic or a paraplegic predominantly rely on military hospitals. The non-service connected patient, again regardless of disability, primarily uses civilian hospitals.

TABLE I.A.3.a: INITIAL HOSPITALIZATION SUMMARY TABLE

	Military	VA	Civilian	Other
Other	37.5	25.0	35.9	1.6
SC - Paraplegic	74.2	8.6	16.4	0.8
NSC - Paraplegic	70.9	5.1	24.1	- 0 -
SC - Quadriplegic	5.0	24.4	68.1	2.5
NSC - Quadriplegic	1.4	16.7	81.9	- 0 - (n=462)

The length of stay in an initial hospital is another important aspect of acute care health systems. A large minority of severely disabled veterans spend less than a year using these initial hospital services. 74% use the initial services up to two years. Table I.A.4. presents information on the length of initial hospitalization for the total sample.

What seems surprising is when we break down the length of initial hospitalization in terms of non-service connected and service connected injury, there is a very significant ($p=.018$ this is very close to being non-significant) difference between length of initial hospitalization for the two groups.

TABLE I.A.4.: LENGTH OF INITIAL HOSPITALIZATION

Length of Hospitalization	Frequency (%)
Less than 1 year	41.9
1 - 2 years	32.1
2 - 3 years	9.8
Longer than 3 years	10.3
Still in hospital	2.2
No answer	3.7 (n=457)

But the results suggest that service connected veterans are slightly more likely to spend extended periods of time in a hospital when they first become injured. Table I.A.5. presents this breakdown of the length of initial hospitalization by the status of the respondents.

TABLE I.A.5.: LENGTH OF INITIAL HOSPITALIZATION AND STATUS

	Service Connected	Non-Service Connected
Less than 1 year	35.7	48.8
1 - 2 years	34.0	30.0
2 - 3 years	12.3	7.0
Greater than 3 years	12.3	8.0
Still in hospital	1.2	3.3 (n=457)

While the status of the individual seems to have some impact on the length of initial hospitalization, the type of disability is a more appropriate variable to employ in the partitioning of the length of initial hospitalization. Table I.A.6. presents the results of this analysis. As would be expected, quadriplegics are more likely to have extended stays in an initial hospital as compared to paraplegics.

TABLE I.A.6.: TYPE OF DISABILITY AND LENGTH OF INITIAL HOSPITALIZATION

	Paraplegic	Quadriplegic	Other
Less than 1 year	46.6	31.1	50.8
1 - 2 years	32.8	33.8	25.4
2 - 3 years	8.9	14.6	0
Greater than 3 years	8.9	14.6	5.1
Still in hospital	0.8	4.0	3.4
No answer	2.0	2.0	15.3 (n=457)

When we look at the distribution of length of initial hospitalization controlling for the type of disability and the status of the respondent, a slightly different pattern emerges. Service connected quadriplegics do not follow the same pattern as the other four categories in the table. Service connected quadriplegics have a much greater chance of having an extended initial hospitalization stay than any other group. Table I.A.7. presents these results.

TABLE I.A.7.
LENGTH OF INITIAL HOSPITALIZATION
WITH TYPE OF INJURY AND DISABILITY

	Length of Initial Hospitalization				
	Less 1 yr.	1-2 yrs.	2-3 yrs.	Greater 3 yrs.	Still NA
Other	50.8	24.6	1.6	4.9	3.3
SC - Para	40.2	36.2	10.2	10.2	0.8
NSC - Para	52.9	29.4	7.6	7.6	0.8
SC - Quad	21.5	32.9	20.3	19.0	2.5
NSC - Quad	41.7	34.7	8.3	9.7	5.6

B. Rehabilitation

The predominant source of rehabilitation services is the VA SCI center. About 70% of all respondents use these centers as their system of rehabilitation. Table I.B.1. presents the findings on place of rehabilitation for the total sample.

TABLE I.B.1.: PLACE OF REHABILITATION

Place of Rehabilitation	Frequency (%)
VA SCI	69.8
Civilian SCI	5.3
Other Civilian Rehab. Centers	7.1
Other	17.8 (n=450)

Looking at the place of rehabilitation in terms of the status of the respondent, a significant difference between non-service connected and service connected respondents emerges. While a significant majority of the two groups rely on VA SCI centers, non-service connected veterans also utilize civilian rehabilitation centers in larger numbers than the service connected respondents. Table I.B.2. presents these results.

TABLE I.B.2.: PLACE OF REHABILITATION AND STATUS OF RESPONDENT

	Other	VA SCI	Civilian SCI	Other Civilian	
Service Connected	22.1	72.9	1.7	3.3	
Non-service Connected	12.9	66.5	9.1	11.5	(n=449)

Civilian rehabilitation centers act as an important secondary source of rehabilitation for the non-service connected. This can also be seen by looking at the mix of users for each of the health delivery services. Table I.B.3. provides the results of this analysis.

TABLE I.B.3: MIX OF REHABILITATION HOSPITAL USAGE BY STATUS OF RESPONDENT

	VA SCI	Civilian SCI	Other civilian	Other	
Service Connected	55.7	17.4	25.0	66.3	
Non-Service Connected	44.3	82.6	75.0	33.7	(n=449)

Table I.B.4. looks at place of rehabilitation for each type of disability in the survey. The quadriplegic and paraplegic respondents follow the same pattern, both rely heavily on VA SCI centers.

TABLE I.B.4.: TYPE OF REHABILITATION HOSPITAL AND TYPE OF DISABILITY

Type of Disability	VA SCI	Civilian SCI	Civilian Rehab.	Other
Paraplegic	74.5	4.9	5.3	15.4
Quadriplegic	77.6	6.1	6.8	9.5

(n=449)

The characteristics found in these two previous tables are summarized in Table I.B.5. which provides information on the place of rehabilitation by status and disability.

TABLE I.B.5.: REHABILITATION HOSPITAL BY INJURY AND DISABILITY

	VA SCI	Civilian SCI	Civilian Rehab.	Other
Other	28.1	7.0	15.8	49.1
SC - Paraplegic	77.7	0.8	1.6	20.3
NSC - Paraplegic	72.0	8.5	9.3	10.2
SC - Quadriplegic	88.2	1.3	0.0	10.5
NSC - Quadriplegic	66.2	11.3	14.1	8.5

(n=449)

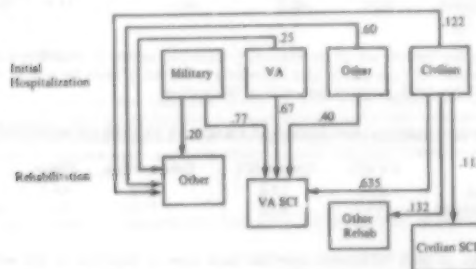
C. Initial Hospitalization and Rehabilitation

Those two health delivery systems - those associated with the initial hospitalization phase and those associated with the rehabilitation phase - can be viewed as component parts of a process. After initial delivery system usage, there is rehabilitation. It would be interesting to look at what initial systems lead to what rehabilitation systems. The flow of this process suggests that all of the initial delivery systems feed directly into the VA SCI center. Illustration I.C. provides a flow chart of severely disabled patient movement from initial hospital systems to rehabilitation systems. This process description is somewhat misleading. In certain circumstances, when an individual is initially admitted to a VA hospital and receives rehabilitation services in a VA SCI center, it is not clear that he physically has been moved from one hospital to another. The individual may be receiving rehabilitation services in the hospital he was first admitted in. This may also occur when an individual's initial hospitalization is a civilian hospital and rehabilitation services occur from civilian sources.

The VA SCI center is the major provider of rehabilitation services, no matter what is the initial source of hospitalization. The only other rehabilitation category with as many links from initial hospitalization is the residual category of "other."

An interesting characteristic of this patient flow is that those patients who are initially placed in a civilian hospital also use non-VA SCI rehabilitation hospitals in greater numbers. This is best seen in the patient make-up of each of the two defined alternative rehabilitation systems. 91.7% of civilian SCI patients had initial treatment in civilian hospitals. 81.3% of individuals in other civilian rehabilitation systems were first hospitalized in civilian hospitals. Table I.C.1 and I.C.2 provide information on these two characteristics.

ILLUSTRATION I.C.1.
FLOW OF PATIENTS FROM INITIAL HOSPITAL TO REHABILITATION HOSPITAL*



*Only flows exceeding 10% of initial hospital sub-population are included. Three patterns were omitted: VA → Civilian SCI = 2.9%, VA → Other = 4.4%, Military → Other = 1.7%. Numbers on flow lines are the per cent of initial hospital patients who are routed to rehabilitation hospital.

TABLE I.C.1.: INITIAL HOSPITAL BY REHABILITATION HOSPITAL

Initial hospital	VA SCI	Rehabilitation hospital			
		Civ. SCI	Civ. rehab.	Other	
Military	77.8	0.0	1.7	20.6	(n=450)
VA	67.6	2.9	4.4	25.0	
Civilian	63.5	11.2	13.2	12.2	
Other	60.0	0.0	0.0	40.0	

TABLE I.C.2.: MAKE-UP OF REHABILITATION HOSPITAL CASELOAD BY SOURCE OF INITIAL HOSPITALIZATION

Initial hospital	VA SCI	Rehabilitation hospital			
		Civ. SCI	Civ. rehab.	Other	
Military	44.6	0.0	9.4	46.3	(n=450)
VA	14.6	8.3	9.4	21.3	
Civilian	35.8	91.7	81.3	30.0	
Other	1.0	0.0	0.0	2.5	

Table I.C.2 underscores the flow process. As can be seen from the table, the two predominant categories for rehabilitation - VA SCI and other - have a heterogeneous caseload. The civilian categories are predominantly supplied by civilian hospitals.

A much more explicit description of this process emerges in looking at sub-groups of respondents. Table I.C.3 and Table I.C.4 present the result of this process for the service connected and the non-service connected sub-populations. What is interesting about this breakdown is that 55.4% of the service connected population moves from military hospitals to VA SCI rehabilitation hospitals. In the non-service connected sub-population, 45.5% of the respondents move from civilian hospitals to the VA SCI rehabilitation hospitals. (These figures are for entire sub-populations and can not be found directly from the tables in this analysis.) In looking at the mix of rehabilitation hospital patients there is a substantial difference between these two sub-groups. For the service connected, the caseload in civilian hospital is not predominated by patients from military hospitals (the most often used initial source of hospitalization for this group). The non-service connected sub-population shows a heavy preponderance on civilian health systems.

TABLE I.C.3.: INITIAL HOSPITALIZATION BY REHABILITATION HOSPITALIZATION CONTROLLING FOR STATUS

	Service connected					Non-service connected				
	VA SCI	Civ. SCI	Civ. Rehab.	Other		VA SCI	Civ. SCI	Civ. Rehab.	Other	
Military	77.8	-0-	1.8	20.5	(n=171)	77.8	-0-	-0-	22.2	(n=9)
VA	52.4	4.8	9.5	33.3	(n=21)	74.5	2.1	2.1	21.3	(n=41)
Civilian	63.8	6.4	6.4	23.4	(n=47)	63.8	12.1	15.4	8.7	(n=149)
Other	100.0	-0-	-0-	-0-	(n=1)	50.0	0.0	0.0	50.0	(n=4)
					n=240					n=209

TABLE I.C.4.: CASELOAD MIX OF REHABILITATION HOSPITAL BY INITIAL HOSPITAL CONTROLLING FOR VETERAN STATUS

	Service connected					Non-service connected				
	VA SCI	Civ. SCI	Civ. Rehab.	Other		VA SCI	Civ. SCI	Civ. Rehab.	Other	
Military	76.0	0.0	37.5	66.0		5.0	0.0	-0-	7.4	
VA	6.3	25.0	25.0	13.2		25.2	5.3	4.2	37.0	
Civilian	17.1	75.0	37.5	20.8		68.3	94.7	95.8	48.1	
Other	0.6	0.0	0.0	0.0		1.4	0.0	0.0	7.4	

Most respondents do not live near VA SCI centers; nevertheless, they tend to rely upon the SCI centers for most of their medical care. 46% of the respondents live at a distance greater than 75 miles from these centers. Table I.C.5. presents this breakdown for the entire sample of respondents.

TABLE I.C.5.: DISTANCE FROM VA SCI CENTER

Distance	Frequency (%)
Less than 25 miles	21.6
25-50 miles	17.2
50-75 miles	7.9
75-100 miles	6.4
Greater than 100 miles	39.5
Don't know	7.3

Tables I.C.6. and I.C.7. break down distance from VA SCI centers by the status of a veteran and the type of disability of the respondents. While 43.5% of service connected respondents live within 50 miles of these centers, only 33.5% of the non-service connected respondents live within this distance.

TABLE I.C.6.: DISTANCE FROM VA SCI AND STATUS OF RESPONDENT

Distance from VA SCI	Service Connected	Non-Service Connected
Less than 25	21.5	21.8
25-50	22.0	11.7
50-75	8.3	7.3
75-100	5.7	7.3
Greater than 100	35.8	43.7
Don't know	6.5	8.3

TABLE I.C.7.: DISTANCE FROM VA SCI AND TYPE OF DISABILITY

Distance	Paraplegic	Quadriplegic	Other
Less than 25	18.4	22.6	32.3
25-50	15.6	18.5	21.0
50-75	8.2	6.2	9.7
75-100	8.2	4.1	4.8
Greater than 100	43.4	42.5	17.7
Don't know	6.1	6.2	14.5

II. CONTINUING CARE

The investigation of continuing care will employ information about inpatient and outpatient histories as well as the usage of other medical services and private doctors. These categories have been included under the rubric of continuing care because of the needs of the severely disabled individual. That is, the frequent usage of inpatient and outpatient facilities by this group are routine as compared to the larger population. These delivery systems are necessary to maintain the severely disabled veteran over the long run.

A. Inpatient care

About 48% of all those sampled returned to the hospital as an inpatient at least once a year. Table II.A.1 shows the frequency of inpatient health system usage for the entire sample.

TABLE II.A.1.: INPATIENT HISTORY

No. of visits per year	Frequency (%)
Greater than twice	12.9
Twice	13.1
Once	21.7
Less than once	34.1
Not been back	7.9
No answer	10.3 (n=465)

When one compares NSC/SC respondents, a weak relationship emerges. Table II.A.2 presents these results. Non-service connected injured individuals are more likely to visit a hospital as an inpatient more frequently than service connected respondents.

TABLE II.A.2.: INPATIENT HISTORY BY TYPE OF INJURY

	More than twice	Twice	Once	Less than once	Not been back
Service connected	9.8	11.0	20.0	40.8	7.8
Non-service connected	16.6	15.6	23.7	26.1	8.1

Over 50% of the non-service connected respondents fall within the first three categories as compared to 40% of the service connected respondents. One obvious reason for this type of pattern might be the type of disability. Table II.A.2.a presents the relationship between the type of disability and inpatient history.

TABLE II.A.2.a.: TYPE OF DISABILITY AND INPATIENT HISTORY

	More than twice	Twice	Once	Less than once	Not been back
Paraplegic	14.6	12.6	22.3	34.8	6.5
Quadruplegic	11.3	15.9	23.2	32.5	7.3
Other	10.3	8.6	15.5	34.5	15.5

There is no significant difference between sub-groups based on type of disability. This lack of a relationship also exists between the status of an injured respondent and the type of disability the respondent has incurred. Table II.A.3 provides information on this correspondence.

TABLE II.A.3.: STATUS AND DISABILITY

	Paraplegic	Quadruplegic	Polio	MS	Other
Service connected	51.4	31.7	4.8	7.6	4.4
Non-service connected	56.1	33.6	4.2	4.2	1.9

These last two tables suggest that disability and status do not interact and bias the earlier results on inpatient history. In order to be sure a table has been produced which breaks down the sample by type of disability and the status of respondent, these results are reproduced in Table II.A.4. As can be seen in this table, the lack of a relationship between the type of disability is maintained. The largest factor in the table for the different distributions is not the type of disability but the status of the respondent. Table II.A.4 presents these results.

TABLE II.A.4.: FREQUENCY OF INPATIENT CARE

	More than twice	Twice	Once	Less than once	Not been back
SC - Paraplegic	10.9	8.6	23.4	39.9	6.3
NSC - Paraplegic	18.6	16.9	21.2	28.8	6.8
SC - Quadruplegic	6.3	17.7	19.0	40.5	7.6
NSC - Quadruplegic	16.7	13.9	27.8	23.6	6.9

Another way to consider these effects is to look at the percentage difference of two categories. By comparing SC and NSC paraplegics and SC and NSC quadruplegics we are able to test for the importance of eligibility status. By comparing SC para and SC quad, NSC para and NSC quad we can test for the importance of the type of disability. Table II.A.4.a presents the differences. A simple summary statistic for comparative purposes could be the total percentage difference. The largest differences occur when we test for the importance of the eligibility status. This simple test (which does not test for statistical significance) suggests that eligibility status - what type of injury - service connected or non-service connected - is more important in explaining the difference in inpatient history than the type of disability.

TABLE II.A.4.a.: PERCENTAGE DIFFERENCE - FREQUENCY OF INPATIENT CARE

Test for Eligibility	FREQUENCY OF INPATIENT CARE					Total
	More than twice	Twice	Once	Less than twice	Not been back	
SC-NSC Para (% dif.)	7.7	8.3	2.2	11.1	0.5	29.8
SC-NSC Quad (% dif.)	10.4	3.8	8.8	14.9	0.7	38.6
Test for Disability						
SC Para-SC Quad (% dif.)	4.6	9.1	4.4	0.6	1.3	20.0
NSC Para-NSC Quad (% dif.)	1.9	3.0	6.6	5.2	0.1	16.8

One factor which might also explain these results on the frequency of inpatient hospitalization would be the reason for the use of the hospital. Table II.A.5 presents five reasons for the use of inpatient hospitalization and the frequencies for the total population in response to these reasons. Table II.A.6 breaks down these reasons for the NSC and SC sub-populations. In trying to run an efficient inpatient health delivery system an administrator would undoubtedly look at those type reasons which unduly inflate inpatient hospitalization. In the reasons for inpatient hospitalization listed in Table II.A.5 only surgery is a reason which would not increase the number of reasons for visits. Ulcers, therapy and check-ups have some recurring aspect. Ulcers may be chronic recurring problems. Therapy and check-ups can also result in an inflated incidence rate. From Table II.A.5 we see that check-ups and bowel/bladder problems are the largest reasons cited for inpatient care.

Table II.A.6 suggests that there is no real difference in the reason for inpatient care between the service connected and non-service connected sub-populations. A more realistic breakdown of these reasons should be based on the type of disability. Table II.A.7 presents the results of this analysis. There are only two reasons which show a significant difference between type of disabilities.

TABLE II.A.5.: REASONS FOR INPATIENT TREATMENT*

Hospitalized for therapy	11.3%
Hospitalized for surgery	23.2%
Hospitalized for decubitus ulcers	16.3%
Hospitalized for bowel/bladder problems	45.3%
Hospitalized for regular check-ups	50.5%
Not been back as inpatient	17.2%

*N=461, percentage is percentage positive response to each of these separate questions. The percentage will not sum to 100% as a result.

TABLE II.A.6.: INPATIENT TREATMENT BY SC/NSC*

	Therapy		Surgery		Decubitus Ulcers	
	Yes	No	Yes	No	Yes	No
SC	10.4	89.6	23.7	76.3	17.3	82.7
NSC	12.3	87.7	22.7	77.3	15.2	84.8
	Bowel/bladder		Check-up			
	Yes	No	Yes	No	Yes	No
SC	48.2	51.8	52.2	47.8		
NSC	41.7	58.3	48.8	51.2		

*N=460, each question asked separately

TABLE II.A.7.: REASON FOR INPATIENT CARE BY TYPE OF DISABILITY

	Therapy		Surgery		Decubitus Ulcers	
	Yes	No	Yes	No	Yes	No
Paraplegic	12.1	87.9	26.6	73.4	22.2	77.8
Quadriplegic	10.1	89.9	20.1	79.9	11.4	88.6
Other	11.1	88.9	17.5	82.5	4.8	95.2

	Bowel/bladder		Check-up	
	Yes	No	Yes	No
Paraplegic	46.4	53.6	54.8	45.2
Quadriplegic	46.3	53.7	52.3	47.7
Other	38.1	61.9	30.2	69.8

Ulcers are much more predominant in the paraplegic sub-population than the other two categories. Also, paraplegics and quadriplegics are much more likely to be admitted as inpatients for regular checkups than the residual disability category.

B. Outpatient Care

Table II.B.1 presents the distribution of usage of outpatient facilities for the entire sub-population. 49% of the respondents use outpatient services at least twice a year. Only about 10% have not been back to outpatient clinics after their initial usage.

TABLE II.B.1.: OUTPATIENT HISTORY

	Frequency
Daily	2.0
Weekly	4.0
Monthly	16.3
Twice a year	26.8
Yearly	12.3
Less than once a year	15.2
Not been back	9.5
No answer	14.1

n=455

When one breaks down outpatient history by status of injury there are only slight differences in the distribution of usage of outpatient clinics. Table II.B.2 shows this crosstabulation. Another source of outpatient usage would be the type of disability. Table II.B.3 shows this analysis.

TABLE II.B.2.: OUTPATIENT HISTORY BY STATUS OF INJURY

	Daily	Weekly	Monthly	Twice a Year	Yearly	Less than once a yr.	Not been back	No answer
SC	2.5	2.0	17.2	27.5	14.3	17.6	7.8	11.1
NSC	1.4	6.2	15.2	25.7	10.0	12.4	11.4	17.6

TABLE II.B.3.: OUTPATIENT HISTORY BY TYPE OF DISABILITY

	Daily	Weekly	Monthly	Twice a Year	Yearly	Less than once a yr.	Not been back	No answer
Para	2.0	4.5	17.5	28.9	11.8	16.7	7.3	11.4
Quad	2.0	2.7	16.0	22.7	12.0	16.0	10.7	18.0
Other	1.7	5.2	12.1	27.6	15.5	6.9	15.5	15.5

Again, neither crosstabulation shows a big difference between the sub-groups under consideration.

C. Sources of payment for hospitalization

Given the extensive usage of health care facilities and the continually rising cost of these facilities it is necessary to investigate the source of payment for health services for veterans. Table II.C.1 provides a description for the total population on sources of payment for hospitalization. The

VA is the predominant source of hospitalization for the sample. About 71% of the respondents use the VA, and thus do not have to pay for health care. The remaining sources of payment are broken down into many different providers.

TABLE ILC.1: SOURCES OF PAYMENT FOR HOSPITALIZATION

	Frequency
Veteran uses VA	71.1
Veteran uses Mil. Hosp/clinic	2.6
VA fee-basis	8.0
Medicaid/care	6.1
Insurance	4.8
State Medical Benefits	0.4
Pay all himself	1.3
Some assistance, pay a part	3.7
Other	2.0

The most obvious way to break this distribution down is by the status of eligibility. Table ILC.2. presents this analysis. The table shows a statistically significant difference between SC and NSC respondents. But the significance is a result of the difference between the two groups use of secondary sources of hospitalization payment. Both groups show a large majority of respondents relying on the VA, 70.7% of service connected respondents relied on the VA, while 71.8% of the non-service connected relied on the VA as a free source of hospitalization. Some service connected respondents will also use the VA on a fee-basis (12.6%) while the non-service connected respondents will use medicare and medicaid as a secondary source.

TABLE ILC.2: SOURCE OF PAYMENT BY STATUS OF INJURY

	SC	NSC
VA	70.7	71.8
Mil. Hospital and clinic	3.7	1.4
VA fee-basis	12.6	2.8
Medicare/Medicaid	4.1	8.5
Insurance	3.7	6.1
State med. benefits	- 0 -	0.9
Respondent pays	1.2	1.4
Res. Pays w/ assistance	2.0	5.2
Other	2.0	1.9

When we break down the source of payment for hospitalization by the type of disability, there is a difference between the residual group and the quadriplegic and paraplegic sub-populations. While the plegia sub-populations rely on the VA, the residual category is spread out between the VA, VA on a fee-basis, medicare-medicaid and private insurance. Table ILC.3. presents these results.

TABLE ILC.3: SOURCE OF PAYMENT FOR HOSPITALIZATION BY TYPE OF DISABILITY

	Para	Quad	Other
VA	74.3	74.7	48.3
Mil. hosp. and clinic	3.6	1.3	1.7
VA fee-basis	7.2	7.3	13.3
Medicare/Medicaid	3.6	7.3	13.3
Insurance	3.6	4.0	11.7
State med. benefits	0.8	- 0 -	- 0 -
Respondent pays	1.6	0.7	1.7
Respondent pays w/ assistance	3.2	3.3	6.7
Other	2.0	1.3	3.3

D. Hospitalization

A question related to outpatient and inpatient care is what type of hospital do the respondents usually go to. Almost 80% of the respondents said they relied on VA hospitals. The next category is civilian hospitals where 17.8% of the respondents seek care. Table ILC.1 presents these results.

TABLE II.D.1.: TYPE OF HOSPITAL USUALLY CHOSEN

	Frequency
VA	79.6
Military	1.5
Civilian	17.8
Other	1.1

The lack of variance in this table carries through when there is a breakdown of the type of hospital by status of injury. Table II.D.2 shows this lack of difference.

TABLE II.D.2.: HOSPITAL BY STATUS

	VA	Military	Civilian	Other
SC	78.2	2.4	17.7	1.6
NSC	81.6	0.5	17.4	0.5

When we break down the type of hospital chosen by the type of disability an individual has, a significant difference emerges. The plugia respondents predominantly rely on the VA while the residual group relies on the VA system and civilian hospitals. Table II.D.3 presents these results.

TABLE II.D.3.: HOSPITAL BY DISABILITY

	VA	Military	Civilian	Other
Para	82.3	2.0	15.3	0.4
Quad	83.7	0.7	15.0	0.7
Other	58.3	1.7	35.0	5.0

Since there appears to be such a high dependence on the VA system for hospitalization it would be interesting to see if there was an equally high dependence on the VA for other medical services. Table II.D.4 presents information on the reliance on the VA for medical services. A majority of respondents rely on the VA for all of their medical services. The next largest category uses the VA in addition to private doctors.

TABLE II.D.4.: USE OF VA MEDICAL SERVICES

Degree of Reliance on VA	Frequency
All medical needs	52.1
VA in addition to private doctor	32.0
Rarely use VA	8.1
Never use VA	7.8

When we break this initial distribution down by the status of a respondent's injury, there is a slight difference between the two groups in the categories that do not rely extensively on the VA. Service connected respondents may occasionally use the VA, while the largest number of respondents not using the VA are non-service connected. Table II.D.5 shows these results.

TABLE II.D.5.: USE OF VA MEDICAL SERVICE

	All needs	VA & private Dr.	Rarely	Never
SC	52.4	32.9	10.2	4.5
NSC	51.9	31.3	5.7	10.8

If we break down usage by type of disability, no significant difference emerges between groups.

Still another source of medical care is the private physician. 67% of the respondents seek medical care from private physicians. Controlling for the status of the respondent does not alter this relationship. Non-service connected and service connected respondents each utilize private doctors in the same proportions. Likewise, type of disability does not alter usage of private physicians. When one looks at sources of payment for private physicians type of disability does not alter the distribution of sources. Table II.D.6 presents the distribution over the type of sources of payment for private doctors for all respondents. Most respondents either pay their own bills or rely on the VA on a fee-basis to meet the health needs associated with the use of a private physician.

TABLE II.D.6.: SOURCES OF PAYMENT FOR PRIVATE DOCTOR

	Frequency
Private insurance	7.3
Medicare/medicaid	9.8
VA fee-basis	29.8
Pay own bills	30.7
Other	3.2
No answer	19.3 (n=440)

When one looks at these sources of payment controlling for the status of a respondent, a significant difference emerges. Non-service connected respondents are more dependent on private insurance or medicare/medicaid sources. Service connected respondents utilize the VA system on a fee-basis in greater numbers. Table II.D.7 presents these results.

TABLE II.D.7.: SOURCES OF PAYMENT FOR PRIVATE DOCTORS AND STATUS OF VETERAN

	Private insurance	Medicare/medicaid	VA fee-basis	Pay own	Other	No answer
SC	4.2	5.8	35.0	31.3	2.9	20.8
NSC	11.1	14.6	23.6	29.6	3.5	17.6 (n=439)

Perhaps a final note on the dependence of the severely disabled veteran on the VA is in order. An overwhelming 74.4% of all respondents use VA medical services. Over 64% use VA outpatient health care. When one controls for the type of disability and the status of the veteran, the only group which does *not* rely as heavily on the VA is the residual group composed of polio, ms, and other disabilities. While this group is not as totally dependent on the VA, a majority (57.1%) still have utilized VA facilities. This is significantly different than the 75% usage of the other categories, but it still is a large segment of this sub-population.

